CHILDREN'S REHABILITATIVE SERVICES 2007 FAMILY CENTERED SURVEY

INTRODUCTION

The mission of the ADHS Children® Rehabilitative Services (CRS) program is to improve the quality of life for children by providing family centered medical treatment, rehabilitation, and related support services to enrolled individuals who have certain medial, handicapping, or potentially handicapping situations. The program provides preventive and urgent care related to specific qualifying medical conditions. CRS specialists manage the overall care for what are often complicated medical conditions leading to more appropriate utilization of services and minimizing the need for emergency care. Four regional clinics throughout Arizona provide interdisciplinary, multi-specialty care to enrolled members.

The family is the most important participant in the system of care for children with special healthcare needs (CSHCN). Thus, a family perception of the services received through the CRS program is crucial to its administration. The Family Centered Survey was created to evaluate the satisfaction of member families and is conducted annually.

The 2007 survey tool continues to be based on the Consumer Assessment of Healthcare Providers and Systems (CAHPS) 3.0 Medicaid Managed Care Child Questionnaire, with modifications to accommodate the special population and program characteristics of CRS. The telephone survey was administered to a representative sample of active AHCCCS-enrolled CRS members under the age of 21. This year, the overall response rate was 49 percent.

The mean age of children represented by respondents was 8.9 years, with nearly 63 percent of children between the ages of four and fourteen. Fifty-seven percent were male, and 60 percent were of Hispanic or Latino descent. Most of the members (55.0%) spoke English as their main language at home, with an additional 11.0 percent speaking mainly Spanish at home. Twenty-five percent of members spoke both English and Spanish. The most common diagnostic conditions related to nervous system (30.2%), circulatory system (23.6%), sense organs (16.1%), and musculoskeletal/connective tissue disorders (13.2%). More demographic data on respondents can be found in Appendix A.

Additional results from the 2007 survey will be presented in the following sections. Ninety-five percent confidence intervals are denoted by õCI.ö Throughout the document, the number of each question is listed in parentheses to provide for a quick reference to material in the appendices. Please see Appendix A for a description of the study methodology, Appendix B for a copy of the survey tool, Appendix C for a complete breakdown of the responses statewide, Appendix D for a comparison of responses by site, and Appendix E for an evaluation of cultural competency.

OVERALL HEALTH AND RATINGS OF CARE

Overall Care

Respondents were asked to rate their childøs overall health on a five-point scale ranging from excellent to poor (Q31). Nearly 56% of respondents characterized their childrenøs health as excellent or very good, with an additional 30% reporting a health rating of good. Fourteen percent of respondents characterized their childøs health as fair or poor. When asked to rate the overall CRS health care (Q28), with 0 being the worst health care possible and 10 being the best health care possible, the average rating was 9.0

(CI=8.7, 9.2). Differences in ratings between contractor sites were not statistically significant, nor were there significant differences from last years rating (8.9).

Specialty Care

Eighty-six percent of members had seen a CRS specialist in the past 12 months (Q1). Of those members who did not see a CRS specialist, only 10 percent had attempted to get an appointment (Q2). Most parents/guardians (79.5%) reported that it was not a problem to see a CRS specialist that their child needed to see, 14.6 percent said it was a small problem, and 6.0 percent said it was a big problem (Q3). The average rating on a scale from 0 to 10, with 10 being the best specialist possible, was 9.0 (CI=8.9, 9.2). Ninety percent of respondents gave their childøs specialist a score of 8 or higher (Q4). Another 8.1 percent rated their specialist from 4-7, and 2.0 percent rated their specialist between 0 and 3. The differences between results from 2006 to 2007 are not statistically significant.

Table 1. Ouestions Related to Specialty Care

Question	2006	2007
Q1. Saw a CRS specialty doctor in the last 12 months.	85%	86%
Q2. Tried to get an appointment with a CRS specialty doctor in the		
last 12 months.	23%	10%
Q3. It was not a problem to see a CRS specialty doctor that your		
child needed to see in the last 12 months.	77%	80%
Q4. What number would you use to rate your childøs specialty		
doctor?	8.9	9.0

ACCESS TO CARE

Forty-seven percent of respondents called the CRS clinic during regular clinic hours to get help or advice for their child (Q5), the majority of whom (83%) reported usually or always getting the help or advice they needed (Q6). Thirty-six percent of

respondents reported calling the CRS clinic in 2006. This is a significantly lower percentage of callers than in 2007. However, the percentage of callers in 2006 who usually or always received the help they needed (79.2 %) is not significantly different from the 2007 result.

Respondents were also asked about the number of emergency room visits made by their child. Less than 17 percent reported that their children visited an emergency room for their CRS condition (Q9).

AHCCCS has appointment standards for both primary care and specialty care. All of the care delivered at CRS clinics is specialty care, and only those AHCCCS standards that relate specifically to specialty care apply to CRS. The following standards are outlined in the AHCCCS contract with CRS:

- For a CRS recipient with a medically urgent need, the CRS recipient must be seen according to the needs of the member and no later than 72 hours from the request.
- All other clinic appointments must be scheduled within 45 calendar days or less
 of referral, depending on the need of the CRS recipient
 medical condition.
- A recipient
 ø waiting time for an appointment must not exceed 45 minutes, unless
 the provider is unavailable due to an emergency.

32.2% Received Urgent Care within 72 Hours

Urgent requests may involve conditions that are not covered under CRS, in which case the patient is referred back to the primary care physician. When the condition is covered by CRS, a determination is made as to what kind of need the patient has, and whether it is more appropriate to go to a physician of office or be seen at a clinic at the next scheduled visit.

Survey respondents were asked whether in the past year their children oneeded care right away for their CRS conditiono and if so, how long they had to wait to get care at a CRS clinic (Q7). These questions were used to assess compliance with the AHCCCS urgent care standard. However, it is debatable whether the questions are appropriate for the CRS population since CRS clinics do not provide urgent care in the usual sense of the word. Also, needing ocare right awayo may not have been interpreted by respondents as meaning ourgent care.ö

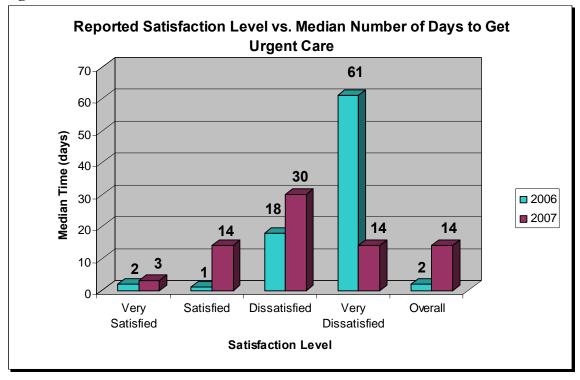
The majority of respondents (54.3%) reported that their child did not need urgent care for their CRS condition. Last year, 64 percent reported that their child did not need urgent care. These results are significantly higher, meaning that more CRS children needed urgent care in 2007 than in 2006. Of those who needed urgent care in 2007, 32.2 percent (CI= 24.7, 39.7) said they were able to get it in a CRS clinic within 72 hours (Q8). This is also significantly different from 2006, where 65.1 percent were able to get urgent care at a CRS clinic within 72 hours. Differences in 2007 compliance rates between contractor sites were not statistically significant.

Nearly 85 percent of respondents reported being satisfied or very satisfied with how long it took to get care (Q7). There were no significant differences in satisfaction level by site. The median¹ time reported to get urgent care was 14 days, with responses ranging from one day to one year. This is significantly different from the 2006 median of two days. Respondents who were dissatisfied had a median wait of 30 days, although very dissatisfied respondents had a median wait of only 14 days.

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¹ In a list of numbers ordered from lowest to highest, the *median* is the number in the middle of the list. It is also known as the 50^{th} percentile.

Figure 1.

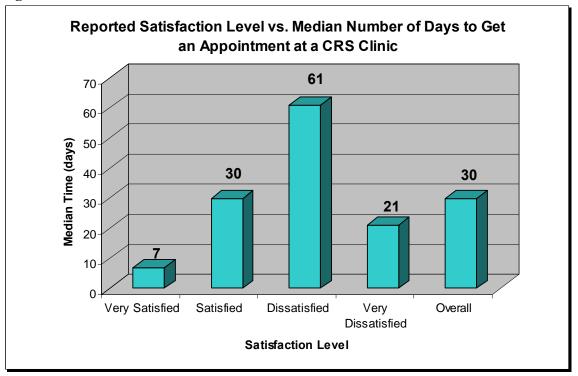


63% Received Appointment within 45 Days

Fifty-eight percent of respondents reported calling a CRS clinic for an appointment in the past 12 months (Q10). Of those, 63.0 (CI=56.2, 69.8) percent were able to get one within 45 days (Q11). The majority (81.1%) reported being satisfied or very satisfied with how long it took to get their appointment. There were no statistically significant differences by site.

The median time that participants reported waiting to get an appointment at a CRS clinic was 30 days, with responses ranging from one day to one year. This is a significant improvement from the 2006 median of 91 days. Very satisfied members had a median wait of seven days, as compared to dissatisfied members with 61 days and very dissatisfied members who had a median wait of 21 days.

Figure 2.



87% Waited Less Than 45 Minutes Before Being Taken to Exam Room

During a CRS specialty clinic appointment, several specialists may see a patient in the same day. It is not uncommon for patients to spend an entire day at the clinic seeing multiple specialists and social workers. When respondents were asked to report their wait time before being taken to the exam room, 87.4 percent (CI=83.0, 91.8) reported that they usually waited 45 minutes or less (Q13). Differences in compliance rates between contractor sites were not statistically significant.

MEMBER SERVICE AND TREATMENT

At CRS clinics, youth say that they do not feel so conspicuously different. Clinic staff know them and understand their conditions. CRS clinics are places where children and youth do not have to explain how they are different and their need for special accommodations.

Several survey items asked about the way that children and their families were treated by clinic staff (see Table 2). Nearly 87 percent of respondents said they were always treated with courtesy and respect (Q14), and 80 percent felt that the clinic staff were always as helpful as they should be (Q15). Similarly high proportions are reported for the remaining customer service measures. Eighty-four percent said that CRS doctors or other health providers always show respect for what they had to say (Q20), 79.7 percent said that CRS doctors and other providers always make it easy to discuss their questions and concerns (Q21), and 80.0 percent said that they always had their questions answered by their CRS providers (Q22).

Table 2. Questions Related to Member Service

Question	2006	2007
Q14. Staff always treated you and your child with courtesy and respect.	85%	87%
Q15. Staff were always as helpful as you thought they should be.	75%	80%
Q20. CRS doctors or other health providers always showed respect for		
what you had to say.	77%	84%
Q21. CRS doctors or other health providers always made it easy for		
you to discuss your questions or concerns.	80%	80%
Q22. You always had your questions answered by your childøs CRS		
doctors or other health providers.	78%	80%

It is widely accepted that having families of children with special health care needs involved in all levels of decision making is a best practice. Several questions were asked regarding the processes by which decisions about the childøs health care were made (see Table 3). Just over half of respondents (52.9%, CI=46.3, 59.5) reported that decisions about their childrenøs health care were made during CRS visits (Q24). Of these respondents, 87 percent reported usually or always being offered choices about their childøs health care (Q25), and 89.8 percent reported usually or always being asked to tell the health care provider what choice they prefer (Q26). Results for both of these

questions are significantly better than those in 2006, which were 76.4 percent and 75 percent, respectively. Like last year, nearly 90 percent of respondents said they were usually or always involved as much as they wanted when decision were made (Q27).

Table 3. Questions Related to Decision-Making

Question	2006	2007
Q24. Decisions about your childøs health care were made during your		
CRS visits in the last 12 months.	53%	53%
Q25. When decisions were made, CRS doctors or other health		
providers usually or always offered you choices about your		
childøs health care.	76%	87%
Q26. When decisions were made, CRS doctors or other health		
providers usually or always asked you to tell them what choices		
you preferred.	74%	90%
Q27. When decisions were made, CRS doctors or other health		
providers usually or always involved you as much as you		
wanted.	90%	90%

Cultural Competency

Communication between families and CRS clinic staff, including the need for translation services, are an important component of a culturally competent program.

Families were asked about the need for and the delivery of translation services, as well as the clinic staff® ability to both listen carefully and explain things in a way that family members could understand. Nearly 80 percent of respondents reported that clinic staff always listen carefully to them (Q16), and a similar proportion (82.7%) reported that clinic staff always explained things to them in a way they could understand (Q19).

Approximately 32 percent of respondents needed an interpreter within the last 12 months (Q29), and 97.2 percent always received translation services when they were requested (Q30). This is a statistically significant increase from the proportion of respondents who always received translation services when needed in 2006 (86.4%).

Two questions from the Mental Health Statistics Improvement Program (MHSIP)

Youth Services Survey were added in 2007 to further evaluate cultural competency.

Respondents were asked to rate their level of agreement to the following statements:

- Q17 Staff respected my family's religious/spiritual beliefs.
- Q18 Staff were sensitive to my cultural/ethnic background.

Sixty-eight percent agreed or strongly agreed that the staff respected their familiesø religious or spiritual beliefs (Q17). The majority of respondents challenged the relevance of this question, claiming the topic of religiosity or spirituality õnever came up.ö Many of the respondents (29%) reported õneutral.ö Less than eight percent reported disagreeing or strongly disagreeing with the statement.

Seventy-three percent agreed or strongly agreed that the staff was sensitive to their cultural/ethnic background (Q18). Respondents challenged the relevance of this question as well, and one quarter of them answered with <code>oneutral.outless</code> than three percent reported disagreeing or strongly disagreeing with the statement.

The results to questions involving cultural competency were also evaluated by racial/ethnic group (see Appendix E). When the responses of White, Non-Hispanic families were examined versus those of minorities, no statistical differences were found. However, when responses were categorized by Hispanic and Non-Hispanic groups, more Hispanics consistently reported positive results:

- A slightly smaller proportion of Non-Hispanics experienced courteous and respectful treatment by CRS staff (91.5%) than Hispanics (97.7%).
- This year, results showed a significant improvement in providers@communication with Hispanic families, with 96.5 percent reporting that they always or usually

understood their providers. In 2006, this proportion was 90.7 percent.

Significantly fewer Non-Hispanics (88.9%) than Hispanics could understand their providers in 2007.

- A high 98.3 percent of Hispanic families reported that they were always or
 usually treated with respect by CRS doctors and other health providers. This is
 significantly lower than the percentage of Non-Hispanic families, of which 89.7
 percent reported respectful treatment.
- The proportion of families with Hispanic members (96.3%) that easily expressed their concerns was significantly higher than that of families with Non-Hispanic members (87.5%).

The responses of survey participants who needed an interpreter were compared to the responses of those who did not need an interpreter. No statistical differences between the groups existed, except among the results of the two MHSIP questions. Eighty-six percent of respondents who needed an interpreter strongly agreed or agreed that staff respected their familiesøreligious or spiritual beliefs (Q17). Only 59 percent of those who did not need an interpreter strongly agreed or agreed with the statement in Q17. More respondents who needed an interpreter (90.8%) reported that staff were sensitive to their cultural or ethnic background than those who did not need an interpreter (62.2%).

COMPARISON TO THE ACUTE CARE HEALTH PLAN CUSTOMER SATISFACTION SURVEY

There exists no benchmark data on populations similar to CRS members.

However, the 2006 Acute Care Health Plan Customer Satisfaction Survey also used questions from the CAHPS 3.0H Medicaid Satisfaction Survey. This provided comparable data to the CRS survey results on eleven questions. As the methodologies of

the surveys were different, the data comparisons should be interpreted with caution. The 2006 Acute Care Health Plan Customer Satisfaction Survey was administered to adults and children who were continuously enrolled in AHCCCS for 6 months and also enrolled at the time of the survey (May 15, 2006 - August 6, 2006). This was done by mail, where the 2007 Family Centered Survey was administered by telephone to members who were continuously enrolled for one year (January 1, 2006 - December 31, 2006). The differences in methodology and wording of survey questions do not provide a basis for statistical testing. However, they can be casually explored for some insight into how satisfaction with CRS services compares to member satisfaction of AHCCCS plans.

The 2007 CRS Family Centered Survey achieved a response rate of 49 percent. Out of eight health plans that participated in the AHCCCS survey, the highest response rate was achieved by APIPA at 34 percent. The difference in response rates may be due to methodology; mail surveys tend to result in fewer responses than those administered by telephone.

CRS Site	Response Rate
Phoenix	44.6%
Tucson	50.6%
Flagstaff	39.5%
Yuma	61.3%
Total	48.6%
(N=716)	(n=348)

Demographics of the CRS population differ from that served by AHCCCS. CRS has a lower percentage of female children enrolled than AHCCCS. The average age of CRS members is about four years younger than that of AHCCCS members.

Table 4. Comparison of Demographics: CRS Children vs. AHCCCS Children

			Cha	racteristi	cs			
	Avg.			Speak	Speak	Excellent		Fair
	Age	Percent	Percent	English	Spanish	or Very	Good	or
	(yrs)	Female	Hispanic	at	at	Good	Health	Poor
				Home	Home	Health		Health
CRS	8.9	43%	60%	80%	36%	56%	30%	14%
AHCCCS	12.5	51%	63%	74%	23%	70%	23%	7%

Respondents were asked to rate their childøs overall health status on a scale of 0-10 (10 being the best possible health). In general, CRS members had lower ratings, which may be expected since children in CRS have complicated special health care needs.

Ratings of Care

In both AHCCCS and CRS surveys, respondents were asked to rate the quality of their specialist and overall health care. A larger proportion of CRS members rated their specialist and overall health care at nine or 10 than both AHCCCS and the National CAHPS Benchmarking Database (NCBD) 2005.

Figure 3.

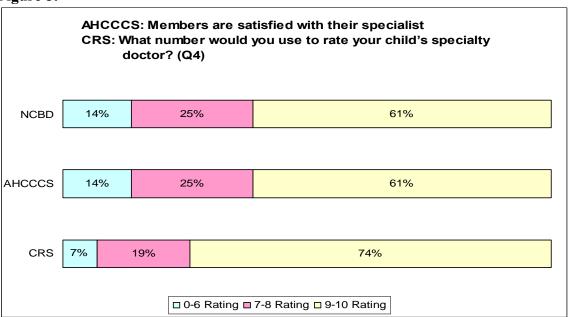
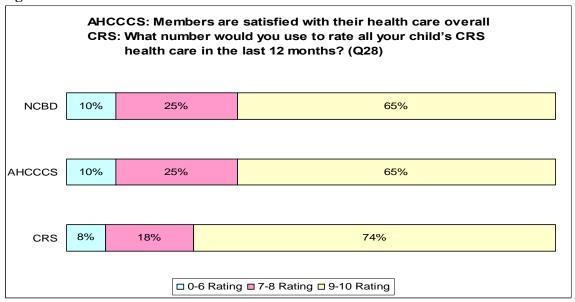


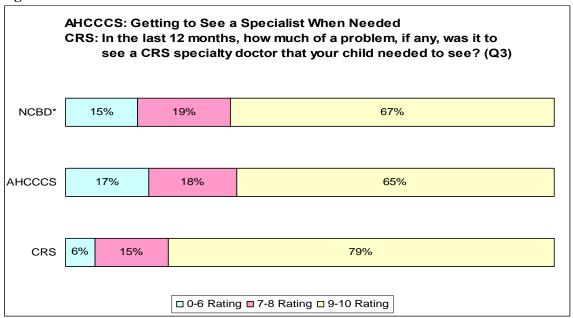
Figure 4.



Access at the Plan Level

Eighty percent of CRS members claimed they had no problem seeing a specialty doctor when needed. This is a 15 percent difference from the proportion of AHCCCS members; only 65 percent of AHCCCS members had no problem getting to see a specialist when needed.

Figure 5.



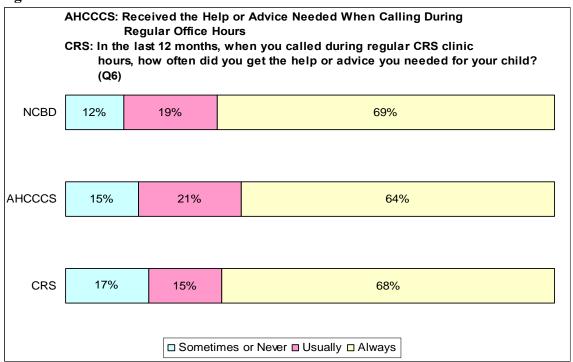
^{*}NCBD percentages do not add to 100% due to rounding.

Access at the Provider Level

Three questions in both CRS and AHCCCS surveys involved access at the provider level. Unfortunately, two of the questions were designed with different response sets; AHCCCS and NCBD used õAlways, Usually, Sometimes or Never,ö while CRS used õVery Satisfied, Satisfied, Dissatisfied or Very Dissatisfied.ö Although the results are not comparable, they will be summarized as background information.

The only issue that was measured with the same response set in both surveys was the availability of telephone assistance during office hours. Neither AHCCCS nor CRS met the average performance of NCBD (69% chose õAlwaysö), although CRS performance was close at 68 percent.

Figure 6.



Respondents of both surveys were asked how quickly they were able to obtain a health care appointment when needed. The results cannot be compared because of the use of different response sets. However, the figures for CRS and AHCCCS are summarized

below for informational purposes. The CRS question did not pertain to appointments for urgent care. It is unknown whether or not the AHCCCS survey included urgent care appointments in this question.

Table 5. Satisfaction with Appointment Availability

AHCCCS: Received an Appointment for Health Care as Soon as Wanted

CRS: In the last 12 months, not counting the times your child needed care right away, how satisfied were you with how long it took to get an appointment at a CRS clinic as soon as you wanted? (Q10)

	CRS	AHCCCS	
Very Satisfied	31%	53%	Always
Satisfied	50%	27%	Usually
Dissatisfied or Very			Sometimes or
Dissatisfied	19%	20%	Never

Survey respondents were asked how often they were taken to the exam room within 15 minutes of their appointment time. The NCBD 2005 averages for each category were 26 percent (always), 29 percent (usually), and 45 percent (sometimes or never).

AHCCCS performed below the NCBD levels at 24 percent (always), 25 percent (usually), and 51 percent (sometimes or never).

The CRS survey used clearly defined time intervals for this response set (< 15 min, 15-30 min, and > 30 min), and the results cannot be directly compared to AHCCCS or NCBD figures. Thirty-five percent of CRS members recalled being taken to the exam room within 15 minutes of their appointment time, with 45 percent of members having to wait between 15 and 30 minutes. Twenty-one percent of CRS members had to wait more than 30 minutes for their appointment to begin.

Table 6. Time in Waiting Room

AHCCCS: Were Taken to the Exam Room Within 15 minutes of Their Appointment Time

CRS: In the last 12 months, when you had an appointment at the CRS clinic, how long after your appointment time did your child have to wait to be taken to the exam room? (Q13)

	CRS	AHCCCS	
Less than 15 min	35%	24%	Always
15-30 min	45%	25%	Usually
More than 30			Sometimes or
minutes	21%	51%	Never

Provider Interactions

Consistently higher proportions of CRS members had positive interactions with providers and staff than AHCCCS members. The table below shows the percentage of members in each plan that chose õAlwaysö as a survey response.

Table 7. Interaction with Providers

	CRS	AHCCCS	NCBD
Doctors/providers explained things in a way members			
could understand	83%	69%	75%
Doctors/providers showed respect for what members had			
to say	84%	73%	76%
Office staff treated members courtesy and respect	87%	74%	79%
Office staff were as helpful as members thought staff			
should be	80%	62%	68%

DISCUSSION

For a second consecutive year, CRS children continue to characterize their overall health status favorably. Eighty-six percent of respondents reported that their children¢s health was excellent, very good, or good, despite their medical challenges. Overall CRS care was rated at an average of 9.0 on a 10-point scale (with 10 being the highest level).

Satisfaction levels remained high in 2007, indicating that families felt they were well-informed, involved in decision-making, and were treated with courtesy and respect by CRS doctors and clinic staff. Between eight and eighteen percent more families in CRS experienced positive provider interactions than respondents from the AHCCCS survey and NCBD.

Information was collected to evaluate compliance with AHCCCS standards for access to care for specialty services. While 87 percent of respondents reported waiting times in the office within standards (45 minutes), compliance was much lower for specialty care and urgent care. Sixty-three percent of respondents were able to obtain an appointment with a specialist within the AHCCCS standard of 45 days. Only 32.2 percent were able to access urgent care within the AHCCCS standard of 72 hours. It is possible that this low compliance rate was a result of misinterpretation of the survey question since respondents were asked about obtaining care oright away. Perhaps this did not mean the same thing as ourgent careo to those who participated in the survey. This possibility is supported by the results of a related question which asked how satisfied respondents were with how long it took to get care right away. In Q7, nearly 85 percent of respondents reported that they were satisfied or very satisfied with how long it took to get care when it was needed right away. It may be helpful in future surveys to use the term ourgent careo or further explain to respondents what kind of care is in question.

A high proportion of wrong numbers was again a problem in the administration of this year's survey. The final response rate was most likely affected by a significantly higher proportion of wrong numbers from Phoenix members (37% in 2007 vs. 26% in 2006). This poses a problem not only for survey purposes, but more importantly, for

contacting patients about their health care. It is unknown whether wrong numbers result from a systematic lack of updating patient information or from patients voluntarily withholding the information; a phone interviewer who also worked on the survey last year reported a heightened awareness and fear of immigration laws among Spanish-speaking respondents.

Thirty percent of respondents required translation of the survey into Spanish and were easily accommodated by phone interviewers. Two respondents requested translation of the survey into another language, one for Polish and one for French. Although translation services were available, there were difficulties involved with scheduling the service around multiple contacts, and these interviews were not completed. For a second year, translation services into a language other than Spanish were not obtained during the survey. This is a needed improvement for future survey administration.

Half (49.7%) of Hispanic respondents needed an interpreter during a clinic visit within the past year. More Hispanics consistently reported positive results pertaining to cultural competency than Non-Hispanics. One interpretation of this finding is CRS staff do not communicate as well with Non-Hispanic members as with Hispanic members. However, it is also possible that the survey results echo a cultural theme that Hispanics are less likely to express dissatisfaction, or are more hesitant to voice their concerns, than Non-Hispanics. Although these differences exist, 90 percent of members or more in all ethnic groups reported high satisfaction levels in 2006 and 2007.

APPENDIX A: METHODOLOGY

Sample Selection

The sampling frame included all CRS members of 21 years of age or less who were continuously enrolled in CRS and an AHCCCS Health Plan between January 1, 2006 and December 31, 2006. Members with a gap in enrollment of more than 30 days were excluded. The sampling frame included a total of 16,330 members. A sample size of 377 was calculated to tolerate no more than a 5% margin of error at a 95% confidence level, using the following formulas:

$$n = {Nx \choose ((N-1)E + x)}^2$$

$$x = z^2 p(1-p)$$

*N was rounded to 20,000 for use in the calculations

where N = number of members in the sampling frame (population)

n = minimum sample size,

z = the distance from the mean associated with confidence level (1.96 for a 95% confidence level),

E = margin of error (.05)

p = the estimated proportion expected to be associated with a given value of a variable (the most conservative assumption = 0.5).

The Family Centered Survey response rate in 2006 was 54%; thus, a conservative 50% response rate was anticipated for 2007. This resulted in 754 sampled members. The simple random sample was drawn using SPSS version 14.0.

Survey Administration

The survey tool is based primarily on the Consumer Assessment of Healthcare Providers and Systems (CAHPS) 3.0 Medicaid Managed Care Child Questionnaire, with modifications to accommodate the special population and program characteristics of CRS (see Appendix B). It also includes two questions from the Mental Health Statistics Improvement Program (MHSIP) Youth Services Survey, which were added to the 2007 version to gather information on cultural competence. The tool was translated into Spanish to accommodate the high percentage of Spanish-speaking families in the CRS program. Two other translation requests were received by members, one for Polish and one for French. Although translation services were available, there were difficulties involved with scheduling the service around multiple contacts, and these interviews were not completed.

The survey was administered by one contracted graduate student from the Sociology Department of Arizona State University, two temporary phone interviewers, and one OCSHCN staff member who conducted interviews with Spanish-speaking respondents. The data entry tool was populated with membersøcontact information and key demographic variables. Interviewers were trained on the data entry tool, and its ability to accurately capture data was verified before survey implementation. In addition, training about the fundamental aspects of how CRS clinics operate was conducted. Some respondents who were reached by phone needed more information about the program or had complaints about their experiences with CRS. For these cases, the interviewer submitted a descriptive form to one of two CRSA staff members for follow-up.

Members were tracked using cards containing their contact information, as well as the date, time and result of each survey attempt. Cards were then organized according to the number of attempts made, need for translation, and the preferred time of day to call the member, when indicated. Up to 12 call attempts were made for each member; calls were made between the hours of 10am to 6pm on weekdays and weekends.

After a first contact was attempted for the entire sample, wrong numbers were identified and listed by clinic sites, who were asked to research the list and send back accurate phone numbers. Survey administration began January 22nd, and continued until March 16th, 2007.

Analysis

Survey data was collected in MS Access and exported to SPSS 14.0 for analysis. Response rates and key outcomes were calculated by site. Within the body of this report, only valid responses are displayed (i.e., valid responses exclude those responses which were either not applicable or missing). Appendix C is a complete breakdown of statewide results including missing values, and Appendix D is a comparison of results by site.

Ninety-five percent confidence intervals were calculated for point estimates using SPSS and the following formula:

$$p \pm z*sqrt[p(1-p)/n]$$

where p = the calculated proportion of a given variable

z = the distance from the mean associated with confidence level (1.96 for a 95% confidence level)

n = the number of respondents

When findings were presented as statistically significant, differences in proportions or means were tested at p < 0.05.

Results

Of the 754 CRS members selected, 398 were successfully contacted, giving an initial response rate of 53%. Thirty-eight respondents stated that they were no longer CRS members, decreasing the total eligible sample to 716. Accounting for refusals to complete the survey and updated eligibility status, 348 surveys were completed, giving an adjusted response rate of 49%. Response rates at the site level varied from a low of 39.5% to a high of 61.3% and were similar to last year areas. Only the response rate for Phoenix was significantly lower (58.7% in 2006). This may be due to an increased proportion of wrong numbers in the sample. Last year, 26% of the phone numbers from Phoenix were wrong numbers. This year, 37% of Phoenix members sampled had wrong numbers. Over one-third (37%) of sampled members from the sites combined could not be reached due to wrong or disconnected numbers.

Table A1: Family Centered Survey Response Rates by Site, n=716

CRS Regional Clinic Site	Number of Sampled Members	Number of Survey Respondents	Response Rate
Phoenix	475	212	44.6%
Tucson	172	87	50.6%
Flagstaff	76	30	39.5%
Yuma	31	19	61.3%

Demographic Characteristics of Respondents vs. Population

The mean age of children represented by respondents was 8.9 years, with nearly 63% of children between the ages of 4 and 14; 57% were male, and 60% were of Hispanic or Latino descent. Most of the members (55.0%) spoke English as their main language at home, with an additional 11.0% speaking mainly Spanish at home. Twenty-five percent of members spoke both English and Spanish. The most common diagnostic

conditions related to nervous system, circulatory system, sense organs, and musculoskeletal/connective tissue disorders.

Without a census, it is possible that the members who completed the survey had different opinions than the CRS population as a whole. This would imply that estimates from the survey data were inaccurate, or *biased*. One way to evaluate the potential for bias is to compare respondents to the original sampling population on known characteristics, such as age, sex, ethnicity, and enrolling diagnosis. Race data was not used as data from the CRS system was inadequate to allow for a comparison; over 80% of respondents had no known race category.

Respondents were similar to the population in terms of age, sex, and most enrolling diagnoses. However, statistically significant differences did exist for ethnicity and two of the largest diagnosis groups. Sixty percent of survey respondents were Hispanic, while only 45% of the CRS population was identified as such. However, the survey data show that similar proportions of Hispanics and Non-Hispanics rated their CRS health care highly, indicating that satisfaction levels do not differ by ethnicity. The data also suggest that satisfaction levels do not differ by enrolling diagnosis. Thus, the difference in proportion of members with nervous system, musculoskeletal, and genitourinary diagnoses between the respondents and the population is not a cause for concern (see Table A2).

Table A2: Demographic Characteristics of Respondents vs. CRS population

Characteristic	Respo	ndents	Popul	ation
	(n=	348)	(N=16	5,330)
	n	%	n	%
Age ó Mean (95% CI)	8.9 (8.3 -9.4)		9.2 (8.9-9.6)	
1-3	65	18.7	3177	19.5
4-9	138	39.7	5914	36.2
10-14	81	23.3	3651	22.4
15-17	40	11.5	2097	12.8
18-21	24	6.9	1491	9.1
Sex				
Male	197	56.6	8868	54.3
Female	151	43.4	7462	45.7
Ethnicity				
Hispanic/Latino descent*	203	59.5	7382	45.2
Not Hispanic/Latino	138	40.5	8948	54.8
Disease Class				
Blood & Blood Forming Organs	0	0.0	84	0.5
Circulatory System	82	23.6	3508	21.5
Congenital Anomalies	3	0.9	218	1.3
Digestive System	25	7.2	1066	6.5
Endocrine, Nutritional, Metabolic	11	3.2	589	3.6
Genitourinary System*	8	2.3	913	5.6
Musculoskeletal/Connective*	46	13.2	2977	18.2
Neoplasm	4	1.1	349	2.1
Nervous System*	105	30.2	4075	25.0
Other	4	1.1	332	2.0
Respiratory System	2	0.6	65	0.4
Sense Organs	56	16.1	2111	12.9
Skin & Subcutaneous Tissue	2	0.6	43	0.3

^{*}Respondents are significantly different from Population

APPENDIX B: FAMILY CENTERED SURVEY, 2007

Family Centered Survey

All information that would let someone identify you or your family will be kept private. The Arizona Department of Health Services, Office for Children with Special Health Care Needs will not share your personal information with anyone without your OK. You may choose to answer this survey or not. If you choose not to, this will not affect the benefits your child receives.

If you want to know more about this survey, please call Thara MacLaren at (602) 542-2881.

Name	e of	the child: Gender of child
Qualif	ying	g Condition:
Paren	t/gu	ardian Name:
Phone	e nu	mber:
	Ph	none disconnected
	No	o answer, RECORD DATE, TIME AND OUTCOME
	Ph	none answered
	yo Yo	Hello, this is (INTERVIEWER NAME)calling from rizona Department of Health Services. We'd like to talk with you about our experiences with the Children's Rehabilitative Services Program. Our answers will help us to make the program better. May I please speak (Parent/Guardian name)?
		If person is parent/guardian, GO TO CONSENT
		No one by that name at this phone number, RECORD DATE, TIME AND OUTCOME
		Not available
		We need to talk with the parent or guardian who lives in this household who knows the most about the health care that (child's name) receives through CRS.
		Would that be you?
		Yes, GO TO SURVEY INTRODUCTION No
		Who would that be? Is he/she available?
		Yes GO TO SURVEY INTRODUCTION No, GO TO CALL BACK
CALL	ВА	ACK:
_ _	PN W Ne	M M eekends eed Spanish speaker ther language

SURVEY INTRODUCTION

We are conducting a satisfaction survey of families who receive health care services through Children's Rehabilitative Services (CRS). Your family has been selected at random to be included in the study. Your answers will help us to make the program better.

You may choose to do this interview or not. If you do, your responses will be kept private. Your decision to do the interview will not affect any benefits you get. The questions should take about 15 minutes to answer.

Do you wish to participate in this survey?
□ Parent/guardian agrees
□ Parent/guardian refuses, Thank them for their time and say good-bye.
IF THE FAMILY MEMBER DOES NOT HAVE TIME TO PARTICIPATE IN THE INTERVIEW NOW, GO TO CALL BACK.
I'd like to begin the interview now, but before we begin, do you have any questions about the survey?
If the parent or guardian has additional questions or concerns have them call Heather Dunn at (602) 364-2286.
Our records show that your child () is now in CRS. Is that right?
 ¹□ Yes ⁰□ No, Thank them for their time

1.	child see doctor? ¹□ Yes	a CRS specialty If Yes, Go to Question 3 If No, Skip Question 4	5.	In the last 12 months, did you call the CRS clinic during regular clinic hours to get help or advice for your child? 1□ Yes 2□ No → If No, Go to Question 7
2.	try to get CRS spec	at 12 months, did you an appointment with a cialty doctor? If No, Go to Question	6.	In the last 12 months, when you called during regular CRS clinic hours, how often did you get the help or advice you needed for your child? 1 Never 2 Sometimes
3.	much of a	t 12 months, how a problem, if any, was		³□ Usually ⁴□ Always
4.	that your ¹ A big ² A sm ³ Not a	a CRS specialty doctor child needed to see? g problem a problem a problem to know your rating of	7.	In the last 12 months, when your child needed care right away for their CRS condition, how satisfied were you with how long it took to get care as soon as you wanted at a CRS clinic?
	the CRS specialty doctor your child saw most often in the last 12 months. Using any number from 0 to 10, where 0 is the worst specialist possible, and 10 is the best specialist possible, what number would you use to rate your child's specialty doctor?			 Very satisfied Satisfied Dissatisfied Very dissatisfied My child did not need urgent care → Go to Question 9
		Worst specialist possible	8.	In the last 12 months, when your child needed care right away for their CRS condition,
	¹ □ 1 ² □ 2 ³ □ 3	p = 0.00.000		most of the time, how long did you have to wait to get care at a CRS clinic?
	⁴ □ 4 ⁵ □ 5 ⁶ □ 6 ⁷ □ 7 ⁸ □ 8 ⁹ □ 9 ¹⁰ □ 10	Rost specialist		□ days □ weeks □ months □ I could not get an appointment
	ы 10	Best specialist possible		

9.	In the last 12 months, how many times did your child go to an emergency room for their CRS condition? One None One 10 1 One 2 One 3 One 4 One 4 One 4 One 5 One 5 One 6 One 7 One 6 One 7	12.	In the last 12 months, not counting the times your child went to an emergency room, how many times did your child go to the CRS clinic? O None → Go to Question 30 1 1 2 2 3 3 4 4 5 5 5 to 9 6 10 or more
10.	In the last 12 months, not counting the times your child needed care right away, how satisfied were you with how long it took to get an appointment at a CRS clinic as soon as you wanted? ¹□ Very satisfied ²□ Satisfied ³□ Dissatisfied ⁴□ Very dissatisfied ⁵□ I did not try to get an appointment → Go to Question 12	13.	In the last 12 months, when you had an appointment at the CRS clinic, how long after your appointment time, did your child have to wait to be taken to the exam room? 1 Less than 15 minutes 2 15 . 30 minutes 3 31 . 45 minutes 4 46 . 60 minutes 5 More than an hour
11.	In the last 12 months, when you called to schedule an appointment for your child at the CRS clinic, most of the time, how long did you have to wait for an appointment?	14.	In the last 12 months, how often did office staff at your child's CRS clinic treat you and your child with courtesy and respect? 1 Never 2 Sometimes 3 Usually 4 Always

15.	In the last 12 months, how often were office staff at your child's CRS clinic as helpful as you thought they should be?	19.	In the last 12 months, how often did your child's CRS doctors or other health providers explain things in a way you could understand?	
	 Never Sometimes Usually Always 		¹ □ Never ² □ Sometimes ³ □ Usually ⁴ □ Always	
16.	In the last 12 months, how often did the CRS clinic staff listen carefully to you? 1 Never 2 Sometimes 3 Usually 4 Always	20.	In the last 12 months, how often did your child's CRS doctors or other health providers show respect for what you had to say? 1 Never 2 Sometimes 3 Usually 4 Always	
17.	Please rate your agreement with the following statement: Staff respected my family's religious/spiritual beliefs.	21.	In the last 12 months, how often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns?	
18.	Please rate your agreement with the following statement: Staff were sensitive to my cultural/ethnic background. 1 Strongly Disagree 2 Disagree 3 Neutral 4 Agree 5 Strongly Agree	22.	In the last 12 months, how often did you have your questions answered by your child's CRS doctors or other health providers? 1 Never 2 Sometimes 3 Usually 4 Always	

23.	In the last 12 months, now often did you get the specific information you needed from your child's CRS doctors or other health providers?	27.	when decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers involve you as much as you wanted?
	 ¹□ Never ²□ Sometimes ³□ Usually ⁴□ Always ⁵□ I didno need any information 		 ¹□ Never ²□ Sometimes ³□ Usually ⁴□ Always
24.	In the last 12 months, were any decisions about your child's health care made during your CRS visits? ¹□ Yes □□ No → If No, Go to	28.	where 0 is the worst health care possible, and 10 is the best health care possible, what number would you use to rate all your child's CRS health care in the last 12 months?
25.	When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers offer you choices about your child's health care? 1 Never 2 Sometimes 3 Usually 4 Always		 O Worst health care possible 1□ 1 2□ 2 3□ 3 4□ 4 5□ 5 6□ 6 7□ 7 8□ 8 9□ 9 10□ 10 Best health care possible
26.	When decisions were made in the last 12 months, how often did your child's doctors or other health providers ask you to tell them what choices you prefer? □ Never □ Sometimes □ Usually □ Always	29.	An interpreter is someone who repeats or signs what one person says in a language used by another person. In the last 12 months, did you need an interpreter to help you speak with your child's CRS doctors or other health providers? ¹□ Yes □□ No → If No, Go to Question 31

30.	In the last 12 months, when you needed an interpreter to help you speak with your child's	34.	What is the highest grade or level of school that you have completed?	
	CRS doctors or other health providers, how often did you get one?		 ¹□ 8th grade or less ²□ Some high school, but did not graduate 	
	¹ □ Never ² □ Sometimes ³ □ Usually		 ³□ High school graduate or GED ⁴□ Some college or 2-year degree 	
	⁴ □ Always		 ⁵□ 4-year college graduate ⁶□ More than 4-year college degree 	
31.	In general, how would you rate your child's overall health now?			
	¹ □ Excellent ² □ Very Good	35.	What language do you mainly speak at home?	
	³□ Good ⁴□ Fair ⁵□ Poor		 ¹□ English ²□ Spanish ³□ Some other language (please print) 	
32.	Is your child of Hispanic or Latino origin or descent?	36.	What language does your child mainly speak at home?	
	Yes, Hispanic or Latino No, Not Hispanic or Latino		 ¹□ English ²□ Spanish ³□ Some other language 	
33.	What is your child's race? Please mark one or more.		(please print)	
	¹ □ White ² □ Black or African-American ³ □ Asian	37.	How are you related to the child?	
	 ⁴□ Native Hawaiian or other Pacific Islander ⁵□ American Indian or Alaska 		 ¹□ Mother or father ²□ Grandparent ³□ Aunt or uncle 	
	Native ⁶ □ Other		⁴ □ Older brother or sister ⁵ □ Other relative	
			⁶ □ Legal guardian ⁷ □ Someone else <i>(please print)</i>	
			Thank you for completing this survey	

APPENDIX C: SURVEY RESPONSES, STATEWIDE

1. In the last 12 months, did your child see a CRS specialty doctor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	49	14.1	14.1	14.1
	Yes	298	85.6	85.9	100.0
	Total	347	99.7	100.0	
Missing	System	1	.3		
Total		348	100.0		

2. In the past 12 months, did you try to get an appointment with a CRS specialty doctor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	44	89.8	89.8	89.8
	Yes	5	10.2	10.2	100.0
	Total	49	100.0	100.0	

3. In the last 12 months, how much of a problem, if any, was it to see a CRS specialty doctor that your child needed to see?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	A big problem	18	5.2	6.0	6.0
	A small problem	44	12.7	14.6	20.5
	Not a problem	240	69.2	79.5	100.0
	Total	302	87.0	100.0	
Missing	System	45	13.0		
Total		347	100.0		

4. What number would you use to rate your child's specialty doctor?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 to 3	6	2.0	2.0	2.0
	4 to 7	24	8.1	8.1	10.1
	8 to 10	267	89.6	89.9	100.0
	Total	297	99.7	100.0	
Missing	System	1	.3		
Total		298	100.0		

Mean = 9.03, Standard Deviation = 1.629

5. In the last 12 months, did you call the CRS clinic during regular clinic hours to get help or advice for your child?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	183	52.6	52.6	52.6
	Yes	165	47.4	47.4	100.0
	Total	348	100.0	100.0	

6. In the last 12 months, when you called during regular CRS clinic hours, how often did you get the help or advice you needed for your child?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	7	4.2	4.2	4.2
	Sometimes	21	12.7	12.7	17.0
	Usually	24	14.5	14.5	31.5
	Always	113	68.5	68.5	100.0
	Total	165	100.0	100.0	

7. In the last 12 months, when your child needed care right away for their CRS condition, how satisfied were you with how long it took to get care as soon as you wanted at a CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Satisfied	51	14.7	32.5	32.5
	Satisfied	82	23.6	52.2	84.7
	Dissatisfied	18	5.2	11.5	96.2
	Very Dissatisfied	6	1.7	3.8	100.0
	Total	157	45.1	100.0	
Missing	My child did not need urgent care	189	54.3		
	System	2	.6		
	Total	191	54.9		
Total		348	100.0		

8. In the last 12 months, when your child needed care right away for their CRS condition, most of the time, how long did you have to wait to get care at a CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Within 3 Days	48	30.6	32.2	32.2
	4-7 days	18	11.5	12.1	44.3
	More than 7 days	76	48.4	51.0	95.3
	Could not get an appointment	7	4.5	4.7	100.0
	Total	149	94.9	100.0	
Missing	System	8	5.1		
Total		157	100.0		

Mean = 34.55 days, Standard Deviation = 62.99 days

9. In the last 12 months, how many times did your child go to an emergency room for their CRS condition?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	None	287	82.5	83.4	83.4
	1	19	5.5	5.5	89.0
	2	19	5.5	5.5	94.5
	3	7	2.0	2.0	96.5
	4	4	1.1	1.2	97.7
	5 to 9	6	1.7	1.7	99.4
	10 or more	2	.6	.6	100.0
	Total	344	98.9	100.0	
Missing	System	4	1.1		
Total		348	100.0		

10. In the last 12 months, not counting the times your child needed care right away, how satisfied were you with how long it took to get an appointment at a CRS clinic as soon as you wanted?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Very Satisfied	63	18.1	31.3	31.3
	Satisfied	100	28.7	49.8	81.1
	Dissatisfied	26	7.5	12.9	94.0
	Very Dissatisfied	12	3.4	6.0	100.0
	Total	201	57.8	100.0	
Missing	I did not try to get an appointment	145	41.7		
	System	2	.6		
	Total	147	42.2		
Total		348	100.0		

11. In the last 12 months, when you called to schedule an appointment for your child at the CRS clinic, most of the time, how did you have to wait for an appointment?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	45 Days or less	121	60.2	63.0	63.0
	46 to 90 days	31	15.4	16.1	79.2
	More than 90 days	35	17.4	18.2	97.4
	Could not get an appointment	5	2.5	2.6	100.0
	Total	192	95.5	100.0	
Missing	System	9	4.5		
Total	<u>'</u>	201	100.0		

Mean = 51.34 days, Standard Deviation = 75.26

12. In the last 12 months, not counting the times your child went to an emergency room, how many times did your child go to the CRS clinic?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	None	50	14.4	14.5	14.5
	1	63	18.1	18.2	32.7
	2	68	19.5	19.7	52.3
	3	53	15.2	15.3	67.6
	4	38	10.9	11.0	78.6
	5 to 9	53	15.2	15.3	93.9
	10 or more	21	6.0	6.1	100.0
	Total	346	99.4	100.0	
Missing	System	2	.6		
Total		348	100.0		

13. In the last 12 months, when you had an appointment at the CRS clinic, how long after your appointment time, did your child have to wait to be taken to the exam room?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Less than 15 minutes	77	34.7	34.7	34.7
	15-30 minutes	99	44.6	44.6	79.3
	31-45 minutes	18	8.1	8.1	87.4
	46-60 minutes	9	4.1	4.1	91.4
	More than an hour	19	8.6	8.6	100.0
	Total	222	100.0	100.0	

14. In the last 12 months, how often did office staff at your child's CRS clinic treat you and your child with courtesy and respect?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	2	.9	.9	.9
	Sometimes	9	4.1	4.1	5.0
	Usually	18	8.1	8.1	13.1
	Always	193	86.9	86.9	100.0
	Total	222	100.0	100.0	

15. In the last 12 months, how often were office staff at your child's CRS clinic as helpful as you thought they should be?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	3	1.4	1.4	1.4
	Sometimes	7	3.2	3.2	4.5
	Usually	34	15.3	15.3	19.8
	Always	178	80.2	80.2	100.0
	Total	222	100.0	100.0	

16. In the last 12 months, how often did the CRS clinic staff listen carefully to you?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	4	1.8	1.8	1.8
	Sometimes	13	5.9	5.9	7.7
	Usually	29	13.1	13.1	20.7
	Always	176	79.3	79.3	100.0
	Total	222	100.0	100.0	

17. Please rate your agreement with the following statement: Staff respected my family's religious/spiritual beliefs.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	6	2.7	2.7	2.7
	Disagree	1	.5	.5	3.2
	Neutral	64	28.8	28.8	32.0
	Agree	96	43.2	43.2	75.2
	Strongly Agree	55	24.8	24.8	100.0
	Total	222	100.0	100.0	

18. Please rate your agreement with the following statement: Staff were sensitive to my cultural/ethnic background.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Strongly Disagree	5	2.3	2.3	2.3
	Disagree	1	.5	.5	2.7
	Neutral	55	24.8	24.8	27.5
	Agree	100	45.0	45.0	72.5
	Strongly Agree	61	27.5	27.5	100.0
	Total	222	100.0	100.0	

19. In the last 12 months, how often did your child's CRS doctors or other health providers explain things in a way you could understand?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	4	1.8	1.8	1.8
	Sometimes	11	5.0	5.0	6.8
	Usually	23	10.4	10.5	17.3
	Always	182	82.0	82.7	100.0
	Total	220	99.1	100.0	
Missing	System	2	.9		
Total		222	100.0		

20. In the last 12 months, how often did your child's CRS doctors or other health providers show respect for what you had to say?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	3	1.4	1.4	1.4
	Sometimes	9	4.1	4.1	5.4
	Usually	24	10.8	10.8	16.2
	Always	186	83.8	83.8	100.0
	Total	222	100.0	100.0	

21. In the last 12 months, how often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	5	2.3	2.4	2.4
	Sometimes	11	5.0	5.2	7.5
	Usually	27	12.2	12.7	20.3
	Always	169	76.1	79.7	100.0
	Total	212	95.5	100.0	
Missing	I didn't have any questions	10	4.5		
Total	Total		100.0		

22. In the last 12 months, how often did you have your questions answered by your child's CRS doctors or other health providers?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	4	1.9	1.9	1.9
	Sometimes	11	5.2	5.2	7.1
	Usually	27	12.7	12.9	20.0
	Always	168	79.2	80.0	100.0
	Total	210	99.1	100.0	
Missing	System	2	.9		
Total		212	100.0		

23. In the last 12 months, how often did you get the specific information you needed from your child's CRS doctors or other health providers?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	6	2.7	3.0	3.0
	Sometimes	11	5.0	5.6	8.6
	Usually	31	14.0	15.7	24.2
	Always	150	67.6	75.8	100.0
	Total	198	89.2	100.0	
Missing	I didn't need any information	23	10.4		
	System	1	.5		
	Total	24	10.8		
Total	- 1 5	222	100.0		

24. In the last 12 months, were any decisions about your child's health care made during your CRS visits?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	104	46.8	47.1	47.1
	Yes	117	52.7	52.9	100.0
	Total	221	99.5	100.0	
Missing	System	1	.5		
Total		222	100.0		

25. When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers offer you choices about your child's health care?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	6	5.1	5.2	5.2
	Sometimes	9	7.7	7.8	13.0
	Usually	13	11.1	11.3	24.3
	Always	87	74.4	75.7	100.0
	Total	115	98.3	100.0	
Missing	System	2	1.7		
Total		117	100.0		

26. When decisions were made in the last 12 months, how often did your child's doctors or other health providers ask you to tell them what choices you prefer?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	7	6.0	6.0	6.0
	Sometimes	5	4.3	4.3	10.3
	Usually	14	12.0	12.0	22.2
	Always	91	77.8	77.8	100.0
	Total	117	100.0	100.0	

27. When decisions were made in the last 12 months, how often did your child's CRS doctors or other health providers involve you as much as you wanted?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Never	2	1.7	1.7	1.7
	Sometimes	10	8.5	8.7	10.4
	Usually	6	5.1	5.2	15.7
	Always	97	82.9	84.3	100.0
	Total	115	98.3	100.0	
Missing	System	2	1.7		
Total		117	100.0		

28. What number would you use to rate your child's CRS care in the last 12 months?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	0 to 3	3	1.4	1.4	1.4
	4 to 7	23	10.4	10.4	11.8
	8 to 10	195	87.8	88.2	100.0
	Total	221	99.5	100.0	
Missing	System	1	.5		
Total		222	100.0		

Mean = 8.96, Standard deviation = 1.70

29. In the last 12 months, did you need an interpreter to help you speak with your child's CRS doctors or other health providers?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	150	67.6	67.6	67.6
	Yes	72	32.4	32.4	100.0
	Total	222	100.0	100.0	

30. In the last 12 months, when you needed an interpreter to help you speak with your child's CRS doctors or other health providers, how often did you get one?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Sometimes	1	1.4	1.4	1.4
	Usually	1	1.4	1.4	2.8
	Always	70	97.2	97.2	100.0
	Total	72	100.0	100.0	

31. In general, how would you rate your child's overall health now?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Excellent	64	18.4	18.5	18.5
	Very Good	129	37.1	37.3	55.8
	Good	105	30.2	30.3	86.1
	Fair	42	12.1	12.1	98.3
	Poor	6	1.7	1.7	100.0
	Total	346	99.4	100.0	
Missing	System	2	.6		
Total		348	100.0		

32. Is your child of Hispanic or Latino origin or descent?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	No	138	39.7	40.5	40.5
	Yes	203	58.3	59.5	100.0
	Total	341	98.0	100.0	
Missing	System	7	2.0		
Total		348	100.0		

33. What is your child's race?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	White	101	29.0	29.0	29.0
	Black	10	2.9	2.9	31.9
	Asian	4	1.1	1.1	33.0
	Refused	11	3.2	3.2	36.2
	Hawaiian/Pacific Islander	5	1.4	1.4	37.6
	American Indian	22	6.3	6.3	44.0
	Other	181	52.0	52.0	96.0
	Multi-racial	14	4.0	4.0	100.0
	Total	348	100.0	100.0	

34. What is the highest grade or level of school that you have completed?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	8th Grade or less	39	11.2	11.4	11.4
	Some high school, but did not graduate	64	18.4	18.7	30.0
	High school graduate or GED	98	28.2	28.6	58.6
	Some college or 2-year degree	105	30.2	30.6	89.2
	4-year college graduate	29	8.3	8.5	97.7
	More than 4-year college degree	8	2.3	2.3	100.0
	Total	343	98.6	100.0	
Missing	System	5	1.4		
Total		348	100.0		

35. What language do you mainly speak at home?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	English	190	54.6	55.1	55.1
	Spanish	114	32.8	33.0	88.1
	English & Spanish	35	10.1	10.1	98.3
	Punjabi	1	.3	.3	98.6
	Vietnamese	1	.3	.3	98.8
	Navajo	3	.9	.9	99.7
	Sign language	1	.3	.3	100.0
	Total	345	99.1	100.0	
Missing	System	3	.9		
Total		348	100.0		

36. What language does your child mainly speak at home?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	English	180	51.7	55.0	55.0
	Spanish	36	10.3	11.0	66.1
	English & Spanish	83	23.9	25.4	91.4
	Nonverbal	10	2.9	3.1	94.5
	Sign language	17	4.9	5.2	99.7
	Not speaking yet	1	.3	.3	100.0
	Total	327	94.0	100.0	
Missing	System	21	6.0		
Total		348	100.0		

37. How are you related to the child?

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Mother or father	322	92.5	94.2	94.2
	Grandparent	6	1.7	1.8	95.9
	Aunt or uncle	4	1.1	1.2	97.1
	Legal guardian	9	2.6	2.6	99.7
	Someone else	1	.3	.3	100.0
	Total	342	98.3	100.0	
Missing	System	6	1.7		
Total		348	100.0		

APPENDIX D: SURVEY RESPONSES BY SITE

	Question	Phoe	enix	Tuc	son	Flag	staff	Υι	ıma	A	.II
1.	In the last 12 months, did your child see a CRS specialty doctor? Yes No	185 26	(87.7) (12.3)	74 13	(85.1) (14.9)	23 7	(76.7) (23.3)	16 3	(84.2) (15.8)	298 49	(85.9) (14.1)
2.	In the past 12 months, did you try to get an appointment with a CRS specialty doctor? Yes No	2 24	(7.7) (92.3)	1 12	(7.7) (92.3)	2 5	(28.6) (71.4)	0 3	(0.0) (100.0)	5 44	(10.2) (89.8)
3.	In the last 12 months, how much of a problem, if any, was it to see a CRS specialty doctor that your child needed to see? A big problem A small problem Not a problem	12 27 147	(6.5) (14.5) (79.0)	3 11 61	(4.0) (14.7) (81.3)	2 5 18	(8.0) (20.0) (72.0)	1 1 14	(6.3) (6.3) (87.5)	18 44 240	(6.0) (14.6) (79.5)
4.	What number would you use to rate your child's specialty doctor? Mean ± sd 0 - 3 4 - 7 8 - 10	9.0±1.7 4 15 165	(2.2) (8.2) (89.7)	9.4±1.1 0 5 69	(0.0) (6.8) (93.2)	8.6±2.2 1 2 20	(4.3) (8.7) (87.0)	8.5±2.3 1 2 13	(6.3) (12.5) (81.3)	9.0±1.6 6 24 267	(2.0) (8.1) (89.9)
5.	Did you call the CRS clinic during regular clinic hours to get help or advice for your child? Yes No	103 109	(48.6) (51.4)	38 49	(43.7) (56.3)	17 13	(56.7) (43.3)	7 12	(36.8) (63.2)	165 183	(47.4) (52.6)
6.	How often did you get the help or advice you needed for your child? Never Sometimes Usually Always	6 13 16 68	(5.8) (12.6) (15.5) (66.0)	0 5 3 30	(0.0) (13.2) (7.9) (78.9)	1 2 4 10	(5.9) (11.8) (23.5) (58.8)	0 1 1 5	(0.0) (14.3) (14.3) (71.4)	7 21 24 113	(4.2) (12.7) (14.5) (68.5)
7.	When your child needed care right away for their CRS condition, how satisfied were you with how long it took to get care as soon as you wanted at a CRS clinic? Very Satisfied Satisfied	30 53	(30.3) (53.5)	16 17	(43.2) (45.9)	2 10	(15.4) (76.9)	3 2	(37.5) (25.0)	51 82	(32.5) (52.2)
	Dissatisfied Very Dissatisfied	12 4	(12.1) (4.0)	3 1	(8.1) (2.7)	0	(0.0) (7.7)	3 0	(37.5) (0.0)	18 6	(11.5) (3.8)

	Question	Pho	enix	Tuc	son	Flaç	gstaff	Υι	ıma		All
8.	When your child needed care right away for their CRS condition, how long did you have to wait to get care at a CRS clinic? Within 3 days 4 - 7 days More than 7 days Could not get an appt	31 12 49 4	(32.3) (12.5) (51.0) (4.2)	11 5 15 2	(33.3) (15.2) (45.5) (6.1)	4 1 7 0	(33.3) (8.3) (58.3) (0.0)	2 0 5	(25.0) (0.0) (62.5) (12.5)	48 18 76 7	(32.2) (12.1) (51.0) (4.7)
9.	In the last 12 months, how many times did your child go to an emergency room for their CRS condition? None 1 2 3 4 5 to 9 10 or more	172 13 12 6 3 4	(81.5) (6.2) (5.7) (2.8) (1.4) (1.9) (0.5)	75 3 6 1 0 0	(88.2) (3.5) (7.1) (1.2) (0.0) (0.0) (0.0)	23 1 1 0 1 2	(79.3) (3.4) (3.4) (0.0) (3.4) (6.9) (3.4)	17 2 0 0 0	(89.5) (10.5) (0.0) (0.0) (0.0) (0.0) (0.0)	287 19 19 7 4 6	(83.4) (5.5) (5.5) (2.0) (1.2) (1.7) (0.6)
10.	How satisfied were you with how long it took to get an appointment at a CRS clinic as soon as you wanted? Very Satisfied Satisfied Dissatisfied Very Dissatisfied	28 60 15 8	(25.2) (54.1) (13.5) (7.2)	27 24 9 2	(43.5) (38.7) (14.5) (3.2)	8 12 1	(36.4) (54.5) (4.5) (4.5)	0 4 1	(0.0) (66.7) (16.7) (16.7)	63 100 26 12	(31.3) (49.8) (12.9) (6.0)
11.	When you called to schedule an appointment for your child at the CRS clinic, most of the time, how long did you have to wait for an appointment? 45 days or less 46 to 90 days More than 90 days Could not get an appt	63 18 21 4	(59.4) (17.0) (19.8) (3.8)	39 10 10 0	(66.1) (16.9) (16.9) (0.0)	16 2 3 0	(76.2) (9.5) (14.3) (0.0)	3 1 1	(50.0) (16.7) (16.7) (16.7)	121 31 35 5	(63.0) (16.1) (18.2) (2.6)
12.	Not counting the times your child went to an emergency room, how many times did your child go to the CRS clinic? None 1 2 3 4 5 to 9 10 or more	24 39 46 39 24 26 13	(11.4) (18.5) (21.8) (18.5) (11.4) (12.3) (6.2)	14 14 14 10 9 19	(16.3) (16.3) (16.3) (11.6) (10.5) (22.1) (7.0)	6 6 5 1 4 6 2	(20.0) (20.0) (16.7) (3.3) (13.3) (20.0) (6.7)	6 4 3 3 1 2 0	(31.6) (21.1) (15.8) (15.8) (5.3) (10.5) (0.0)	50 63 68 53 38 53 21	(14.5) (18.2 (19.7) (15.3) (11.0) (15.3) (6.1)

	Question	Pho	enix	Tuc	son	Flag	staff	Υι	ıma	-	All
13.	In the last 12 months, when you had an appointment at the CRS clinic, how long after your appointment time, did your child have to wait to be taken to the exam room? Less than 15 minutes 15-30 minutes 31-45 minutes 46-60 minutes More than an hour	39 71 14 8 16	(26.4) (48.0) (9.5) (5.4) (10.8)	27 16 1 1	(57.4) (34.0) (2.1) (2.1) (4.3)	7 5 3 0	(43.8) (31.3) (18.8) (0.0) (6.3)	4 7 0 0	(36.4) (63.6) (0.0) (0.0) (0.0)	77 99 18 9	(34.7) (44.6) (8.1) (4.1) (8.6)
14.	How often did office staff at your child's CRS clinic treat you and your child with courtesy and respect? Never Sometimes Usually Always	1 4 12 131	(0.7) (2.7) (8.1) (88.5)	0 3 4 40	(0.0) (6.4) (8.5) (85.1)	1 2 1 12	(6.3) (12.5) (6.3) (75.0)	0 0 1 10	(0.0) (0.0) (9.1) (90.9)	2 9 18 193	(0.9) (4.1) (8.1) (86.9)
15.	How often were office staff at your child's CRS clinic as helpful as you thought they should be? Never Sometimes Usually Always	1 4 22 121	(0.7) (2.7) (14.9) (81.8)	0 2 9 36	(0.0) (4.3) (19.1) (76.6)	2 1 2 11	(12.5) (6.3) (12.5) (68.8)	0 0 1 10	(0.0) (0.0) (9.1) (90.9)	3 7 34 178	(1.4) (3.2) (15.3) (80.2)
16.	How often did the CRS clinic staff listen carefully to you? Never Sometimes Usually Always	3 8 16 121	(2.0) (5.4) (10.8) (81.8)	0 3 9 35	(0.0) (6.4) (19.1) (74.5)	1 2 3 10	(6.3) (12.5) (18.8) (62.5)	0 0 1 10	(0.0) (0.0) (9.1) (90.9)	4 13 29 176	(1.8) (5.9) (13.1) (79.3)
17.	Staff respected my family's religious/spiritual beliefs. Strongly Disagree Disagree Neutral Agree Strongly Agree	4 1 40 68 35	(2.7) (0.7) (27.0) (45.9) (23.6)	1 0 17 16 13	(2.1) (0.0) (36.2) (34.0) (27.7)	1 0 4 5 6	(6.3) (0.0) (25.0) (31.3) (37.5)	0 0 3 7 1	(0.0) (0.0) (27.3) (63.6) (9.1)	6 1 64 96 55	(2.7) (0.5) (28.8) (43.2) (24.8)
18.	Staff were sensitive to my cultural/ethnic background. Strongly Disagree Disagree Neutral Agree Strongly Agree	3 1 34 74 36	(2.0) (0.7) (23.0) (50.0) (24.3)	1 0 13 16 17	(2.1) (0.0) (27.7) (34.0) (36.2)	1 0 5 3 7	(6.3) (0.0) (31.3) (18.8) (43.8)	0 0 3 7 1	(0.0) (0.0) (27.3) (63.6) (9.1)	5 1 55 100 61	(2.3) (0.5) (24.8) (45.0) (27.5)

	Question	Pho	enix	Tuc	cson	Fla	gstaff	Υι	ıma	-	All
19.	How often did your child's CRS doctors or other health providers explain things in a way you could understand? Never Sometimes Usually Always	3 7 14 122	(2.1) (4.8) (9.6) (83.6)	0 2 7 38	(0.0) (4.3) (14.9) (80.9)	1 2 2 11	(6.3) (12.5) (12.5) (68.8)	0 0 0 11	(0.0) (0.0) (0.0) (100.0)	4 11 23 182	(1.8) (5.0) (10.5) (82.7)
20.	How often did your child's CRS doctors or other health providers show respect for what you had to say? Never Sometimes Usually Always	2 7 13 126	(1.4) (4.7) (8.8) (85.1)	0 0 8 39	(0.0) (0.0) (17.0) (83.0)	1 2 3 10	(6.3) (12.5) (18.8) (62.5)	0 0 0 11	(0.0) (0.0) (0.0) (100.0)	3 9 24 186	(1.4) (4.1) (10.8) (83.8)
21.	How often did your child's CRS doctors or other health providers make it easy for you to discuss your questions or concerns? Never Sometimes Usually Always	4 7 18 109	(2.9) (5.1) (13.0) (79.0)	0 1 6 40	(0.0) (2.1) (12.8) (85.1)	1 3 2 10	(6.3) (18.8) (12.5) (62.5)	0 0 1 10	(0.0) (0.0) (9.1) (90.9)	5 11 27 169	(2.4) (5.2) (12.7) (79.7)
22.	How often did you have your questions answered by your child's CRS doctors or other health providers? Never Sometimes Usually Always	3 8 16 109	(2.2) (5.9) (11.8) (80.1)	0 2 8 37	(0.0) (4.3) (17.0) (78.7)	1 0 3 12	(6.3) (0.0) (18.8) (75.0)	0 1 0 10	(0.0) (9.1) (0.0) (90.9)	4 11 27 168	(1.9) (5.2) (12.9) (80.0)
23.	How often did you get the specific information you needed from your child's CRS doctors or other health providers? Never Sometimes Usually Always	3 7 19 102	(2.3) (5.3) (14.5) (77.9)	1 3 7 32	(2.3) (7.0) (16.3) (74.4)	1 1 4 10	(6.3) (6.3) (25.0) (62.5)	1 0 1 6	(12.5) (0.0) (12.5) (75.0)	6 11 31 150	(3.0) (5.6) (15.7) (75.8)
24.	Were any decisions about your child's health care made during your CRS visits? Yes No	80 67	(54.4) (45.6)	20 27	(42.6) (57.4)	11 5	(68.8) (31.3)	6 5	(54.5) (45.5)	117 104	(52.9) (47.1)

	Question	Pho	enix	Tuc	son	Flaç	gstaff	Υι	ıma	Δ	JI .
25.	When decisions were made, how often did your child's CRS doctors or other health providers offer you choices about your child's health care? Never Sometimes Usually Always	5 4 8 62	(6.3) (5.1) (10.1) (78.5)	0 4 3 13	(0.0) (20.0) (15.0) (65.0)	1 1 1 7	(10.0) (10.0) (10.0) (70.0)	0 0 1 5	(0.0) (0.0) (16.7) (83.3)	6 9 13 87	(5.2) (7.8) (11.3) (75.7)
26.	When decisions were made, how often did your child's doctors or other health providers ask you to tell them what choices you prefer? Never Sometimes Usually Always	5 3 10 62	(6.3) (3.8) (12.5) (77.5)	1 1 2 16	(5.0) (5.0) (10.0) (80.0)	1 1 2 7	(9.1) (9.1) (18.2) (63.6)	0 0 0 6	(0.0) (0.0) (0.0) (100.0)	7 5 14 91	(6.0) 94.3) (12.0) (77.8)
27.	When decisions were made, how often did your child's CRS doctors or other health providers involve you as much as you wanted? Never Sometimes Usually Always	2 7 4 65	(2.6) (9.0) (5.1) (83.3)	0 2 1 17	(0.0) (10.0) (5.0) (85.0)	0 1 1 9	(0.0) (9.1) (9.1) (81.8)	0 0 0 0 6	(0.0) (0.0) (0.0) (100.0)	2 10 6 97	(1.7) (8.7) (5.2) (84.3)
28.	What number would you use to rate your child's CRS care in the last 12 months? Mean ± sd 0 - 3 4 - 7 8 - 10	9.0±1.7 2 13 132	(1.4) (8.8) (89.8)	9.1±1.3 0 7 40	(0.0) (14.9) (85.1)	8.2±2.8 1 2 13	(6.3) (12.5) (81.3)	9.2±1.3 0 1 10	(0.0) (9.1) (90.9)	9.0±1.7 3 23 195	(1.4) (10.4) (88.2)
29.	Did you need an interpreter to help you speak with your child's CRS doctors or other health providers? Yes No	58 90	(39.2) (60.8)	8 39	(17.0) (83.0)	0 16	(0.0) (100.0)	6 5	(54.5) (45.5)	72 150	(32.4) (67.6)
30.	When you needed an interpreter, how often did you get one? Sometimes Usually Always	0 1 57	(0.0) (1.7) (98.3)	1 0 7	(12.5) (0.0) (87.5)	0 0 0	(0.0) (0.0) (0.0)	0 0 6	(0.0) (0.0) (100.0)	1 1 70	(1.4) (1.4) (97.2)

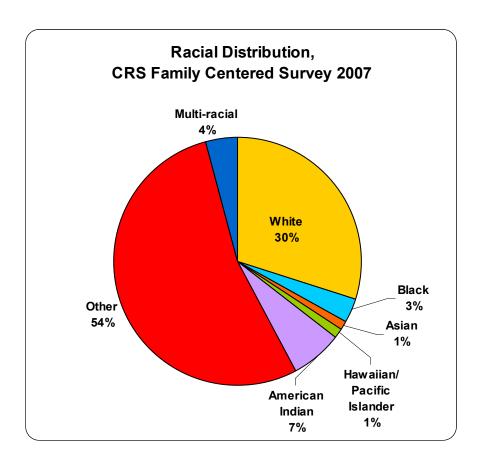
	Question	Pho	enix	Tu	cson	Flag	gstaff	Yu	uma	F	VII .
31.	How would you rate your child's overall health now? Excellent Very Good Good Fair Poor	40 76 61 30	(19.0) (36.0) (28.9) (14.2)	12 34 31 8	(14.0) (39.5) (36.0) (9.3)	9 10 7 3	(30.0) (33.3) (23.3) (10.0)	3 9 6	(15.8) (47.4) (31.6) (5.3)	64 129 105 42	(18.5) (37.3) (30.3) (12.1)
		4	`(1.9)́	1	(1.2)	1	(3.3)	0	(0.0)	6	`(1.7)
32.	Is your child of Hispanic or Latino origin or descent? Yes No	129 79	(62.0) (38.0)	50 35	(58.8) (41.2)	6 24	(20.0) (80.0)	18	(100.0) (0.0)	203 138	(59.5) (40.5)
33.	What is your child's race? White Black Asian Hawaiian/Pacific Islander American Indian Other Multi-racial Refused to answer	61 8 2 2 6 114 10 9	(28.8) (3.8) (0.9) (0.9) (2.8) (53.8) (4.7) (4.2)	29 2 2 1 3 47 2	(33.3) (2.3) (2.3) (1.1) (3.4) (54.0) (2.3) (1.1)	9 0 0 2 13 4 2	(30.0) (0.0) (0.0) (6.7) (43.3) (13.3) (6.7) (0.0)	2 0 0 0 0 16 0	(10.5) (0.0) (0.0) (0.0) (0.0) (84.2) (0.0) (5.3)	101 10 4 5 22 181 14	(29.0) (2.9) (1.1) (1.4) (6.3) (52.0) (4.0) (3.2)
34.	What is the highest grade or level of school that you have completed? 8 th grade or less Some high school High school grad or GED Some college or 2-yr deg. 4-yr college graduate More than 4-yr coll. degree	29 39 59 60 17	(13.9) (18.7) (28.2) (28.7) (8.1) (2.4)	3 15 26 28 11 3	(3.5) (17.4) (30.2) (32.6) (12.8) (3.5)	4 5 6 14 0	(13.8) (17.2) (20.7) (48.3) (0.0) (0.0)	3 5 7 3 1	(15.8) (26.3) (36.8) (15.8) (5.3) (0.0)	39 64 98 105 29	(11.4) (18.7) (28.6) (30.6) (8.5) (2.3)
35.	What language do you mainly speak at home? English Spanish English & Spanish Punjabi Vietnamese Navajo Sign language	106 83 20 1 0 0	(50.2) (39.3) (9.5) (0.5) (0.0) (0.0) (0.5)	54 17 14 0 1 0	(62.8) (19.8) (16.3) (0.0) (1.2) (0.0) (0.0)	24 2 0 0 0 3 0	(82.8) (6.9) (0.0) (0.0) (0.0) (10.3) (0.0)	6 12 1 0 0	(31.6) (63.2) (5.3) (0.0) (0.0) (0.0) (0.0)	190 114 35 1 1 3	(55.1) (33.0) (10.1) (0.3) (0.3) (0.9) (0.3)
36.	What language does your child mainly speak at home? English Spanish English & Spanish Nonverbal Sign language Not speaking yet	100 23 59 8 12	(49.5) (11.4) (29.2) (4.0) (5.9) (0.0)	52 8 16 2 3 0	(64.2) (9.9) (19.8) (2.5) (3.7) (0.0)	25 1 1 0 0	(89.3) (3.6) (3.6) (0.0) (0.0) (3.6)	3 4 7 0 2 0	(18.8) (25.0) (43.8) (0.0) (12.5) (0.0)	180 36 83 10 17	(55.0) (11.0) (25.4) (3.1) (5.2) (0.3)

	Question	Pho	enix	Tuc	son	Flag	staff	Υu	ıma	Α	.II
37.	How are you related to the child? Mother or father Grandparent Aunt or uncle Legal guardian Someone else	199 3 3 2 0	(96.1) (1.4) (1.4) (1.0) (0.0)	78 0 1 6	(90.7) (0.0) (1.2) (7.0) (1.2)	26 3 0 1	(86.7) (10.0) (0.0) (3.3) (0.0)	19 0 0 0	(100.0) (0.0) (0.0) (0.0) (0.0)	322 6 4 9	(94.2) (1.8) 91.2) (2.6) (0.3)

APPENDIX E: CULTURAL COMPETENCY EVALUATION

The 2001 National Survey of Children with Special Health Care Needs estimated that 10.8 percent of children (age 0-17) in Arizona have special care needs. CRS serves many of these children, who come from diverse cultural backgrounds (see Chart 1). In 2007, it was estimated that 60 percent of CRS members are of Hispanic origin. Only 30 percent of members are White, Non-Hispanic, with 70 percent of members belonging to a range of minority groups.

Chart 1.

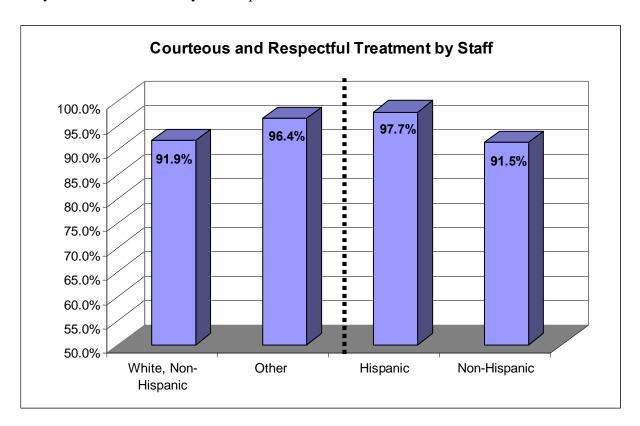


Cultural competency of CRS has been evaluated by using the results of the Family Centered Survey 2007. The telephone survey included eight questions which directly related to cultural competency and five questions that were indirectly related. Among the results of the indirectly related questions, no statistical differences were found between Hispanic and Non-Hispanic members or between White, Non-Hispanics and other minorities. Tables showing these results are included at the end of the document. However, statistical differences were found between racial/ethnic groups for some of the directly related questions.

Results to each question were tabulated in order to compare White, Non-Hispanic members to those who are minorities, and Hispanic members to Non-Hispanic members. Comparisons to other races (Black, Asian, American Indian, and Hawaiian/Pacific Islander) could not be made due to the small number of respondents within each group. Over-sampling may need to be performed in the future to obtain estimates for all races.

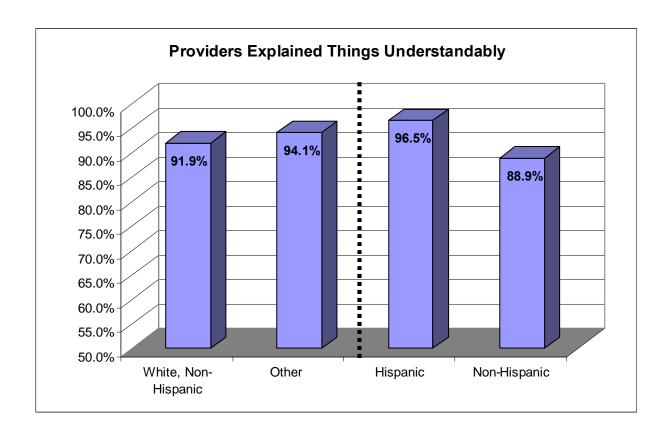
Results

Question 1: In the last 12 months, how often did office staff at your child CRS clinic treat you and your child with courtesy and respect?



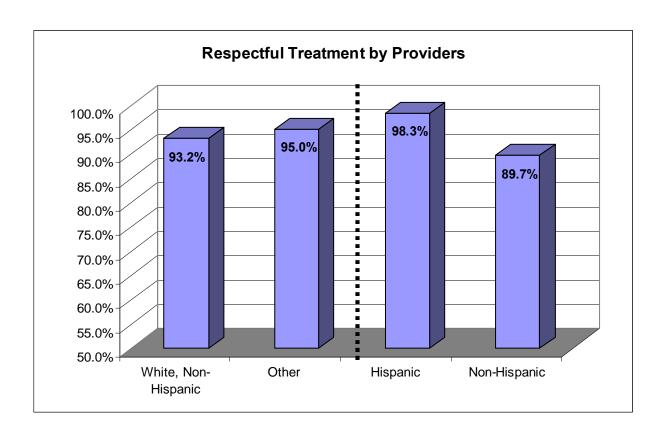
• A high percentage of respondents reported that they always or usually were treated with courtesy and respect by the CRS staff. However, a slightly smaller proportion of Non-Hispanics experienced courteous and respectful treatment by the staff (91.5%) than Hispanics. Although a statistical difference exists between Hispanics and Non-Hispanics, one does not exist between Whites and minorities. The outcomes for this question are not statistically different from the 2006 results.

Question 2: In the last 12 months, how often did your child¢s CRS doctors or other health providers explain things in a way you could understand?



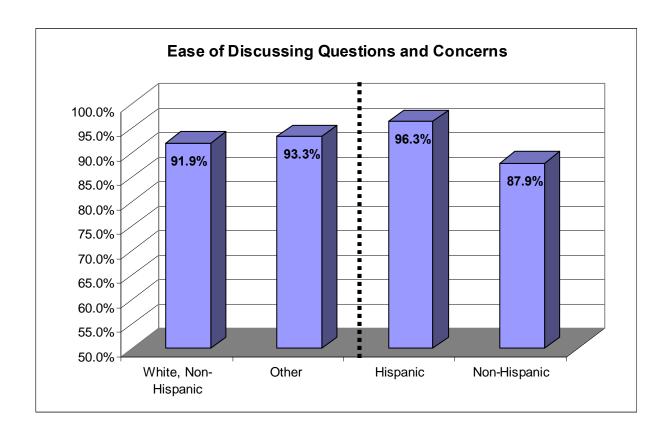
• CRS doctors and other health care providers explained things understandably to both White and minority members. However, a significant difference was found when we compared Hispanics and Non-Hispanics. Approximately 7.6 percent fewer Non-Hispanics could understand their providers than Hispanics. In 2006, 90.7 percent of Hispanic families in CRS always or usually understood their providersøexplanations. This year, results showed a significant improvement in providersøcommunication with Hispanic families, with 96.5 percent reporting that they always or usually understood their providers.

Question 3: In the last 12 months, how often did your child CRS doctors or other health providers show respect for what you had to say?



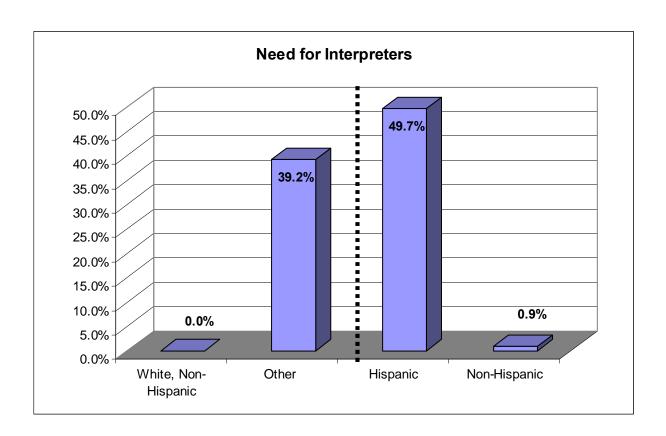
In 2007, providers continued to show respect for what families had to say. A high 98.3
percent of Hispanic families reported that they were always or usually treated with
respect by CRS doctors and other health providers. This is significantly different from the
percentage of Non-Hispanic families, of which 89.7 percent reported respectful
treatment.

Question 4: In the last 12 months, how often did your child CRS doctors or other health providers make it easy for you to discuss your questions or concerns?



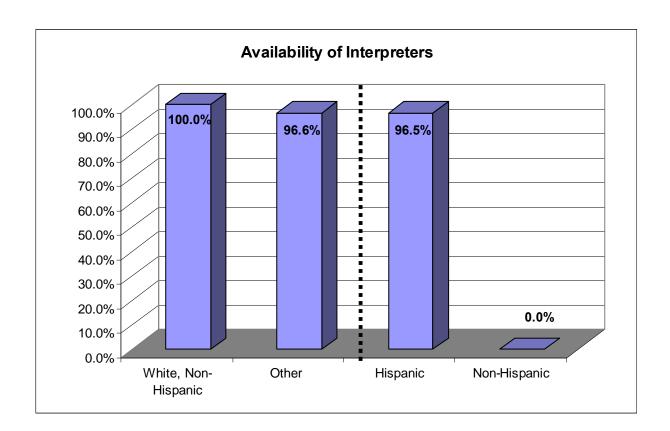
• Over 90 percent of member families contacted through the survey reported that it was always or usually easy to discuss their questions and concerns with providers. The proportion of families with Hispanic members that easily expressed their concerns was significantly higher than that of families with Non-Hispanic members.

Question 5: In the last 12 months, did you need an interpreter to help you speak with your child¢s CRS doctors or other health providers?



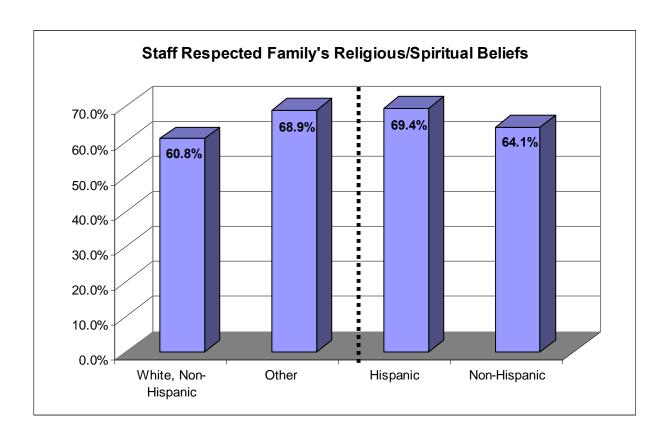
• Very few White and Non-Hispanic members needed an interpreter to assist them. However, similar proportions of Hispanic members and all minorities needed interpreters to speak with providers. Nearly half of Hispanic respondents needed an interpreter within the past year along with 39 percent of minorities.

Question 6: In the last 12 months, when you needed an interpreter to help you speak with your child CRS doctors or other health providers, how often did you get one?



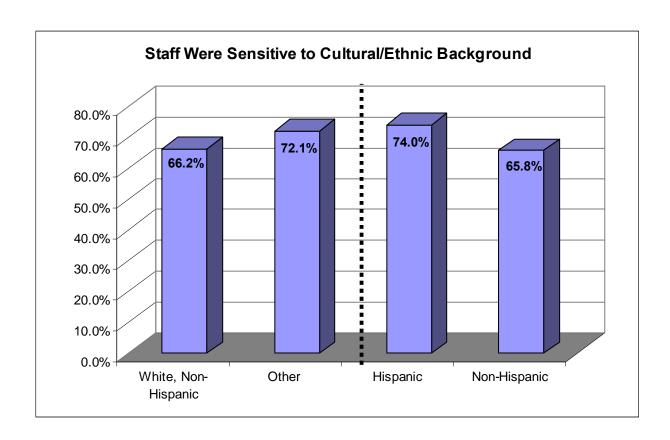
• Due to the small number of members who actually needed an interpreter, statistical differences between the racial/ethnic groups could not be concluded. One Non-Hispanic respondent needed an interpreter and was accommodated only sometimes. Eighty-four minorities indicated that an interpreter was always available to them and eighty-four Hispanics reported likewise. No White, Non-Hispanic members needed an interpreter.

Question 7: Please rate your agreement with the following statement: Staff respected my family's religious/spiritual beliefs.



- This is one of two new questions that were added to the Family Centered Survey in 2007. It was taken from the Mental Health Statistics Improvement Program (MHSIP) Youth Services Survey. Respondents could choose a level of agreement with the statement from the following list: Strongly Disagree, Disagree, Neutral, Agree, Strongly Agree.
- No statistical differences were found between racial/ethnic groups. The percentage of respondents who strongly agreed or agreed that their religious/spiritual beliefs were respected by CRS staff was 60 percent or better across all groups.
- It is unclear how appropriate this question was for use with the CRS population. A large number of respondents indicated that their religious/spiritual beliefs onever came upo in their clinic visits and thus answered oneutralo on the matter.

Question 8: Please rate your agreement with the following statement: Staff were sensitive to my cultural/ethnic background.



• This was another question from (MHSIP) that was added to the survey in 2007. Again, respondents reported that this issue onever came upo in their use of CRS services and often chose oneutralo as their response. However, the feedback was still positive, with at least 65 percent of respondents saying that they strongly agreed or agreed that CRS staff were sensitive to their cultural/ethnic background.

Results to Questions Indirectly Related to Cultural Competency

Table 1. Helpful Staff vs. Ethnicity

			Is your child o Latino origin		
			No	Yes	Total
In the last 12 months, how	Never	Count	1	2	3
often were office staff at your childs CRS clinic as helpful as you thought they should be?		% within Hispanic or Latino	.9%	1.2%	1.0%
	Sometimes	Count	7	4	11
		% within Hispanic or Latino	6.0%	2.3%	3.8%
	Usually	Count	31	17	48
		% within Hispanic or Latino	26.5%	9.8%	16.6%
	Always	Count	78	150	228
		% within Hispanic or Latino	66.7%	86.7%	78.6%
Total		Count	117	173	290
		% within Hispanic or Latino	100.0%	100.0%	100.0%

Table 2. Listens vs. Ethnicity

			Is your child of Latino origin		
			No	Yes	Total
In the last 12 months, how often	Never	Count	2	2	4
did the CRS clinic staff listen carefully to you?		% within Hispanic or Latino	1.7%	1.2%	1.4%
	Sometimes	Count	14	4	18
		% within Hispanic or Latino	12.0%	2.3%	6.2%
	Usually	Count	26	16	42
		% within Hispanic or Latino	22.2%	9.2%	14.5%
	Always	Count	75	151	226
		% within Hispanic or Latino	64.1%	87.3%	77.9%
Total		Count	117	173	290
		% within Hispanic or Latino	100.0%	100.0%	100.0%

Table 3. Providers Answer Questions vs. Ethnicity

			Is your child o		
			No	Yes	Total
In the last 12 months, how	Never	Count	4	0	4
often did you have your questions answered by your childs CRS doctors or other health providers? Sometimes		% within Hispanic or Latino	3.4%	.0%	1.5%
	Sometimes	Count	8	6	14
		% within Hispanic or Latino	6.9%	3.8%	5.1%
	Usually	Count	20	17	37
		% within Hispanic or Latino	17.2%	10.7%	13.5%
	Always	Count	84	136	220
		% within Hispanic or Latino	72.4%	85.5%	80.0%
Total		Count	116	159	275
		% within Hispanic or Latino	100.0%	100.0%	100.0%

Table 4. Providers Give Information vs. Ethnicity

			Is your child o		
			No	Yes	Total
In the last 12 months, how	Never	Count	3	4	7
often did you get the specific information you needed from your childs CRS doctors or other health providers?		% within Hispanic or Latino	2.7%	2.6%	2.7%
	Sometimes	Count	9	4	13
		% within Hispanic or Latino	8.2%	2.6%	5.0%
	Usually	Count	28	18	46
		% within Hispanic or Latino	25.5%	11.9%	17.6%
	Always	Count	70	125	195
		% within Hispanic or Latino	63.6%	82.8%	74.7%
Total		Count	110	151	261
		% within Hispanic or Latino	100.0%	100.0%	100.0%

Table 5. Providers Offer Choices vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
When decisions were made	Never	Count	5	5	10
in the last 12 months, how often did your childs CRS		% within Hispanic or Latino	6.4%	5.7%	6.0%
doctors or other health providers offer you choices	Sometimes	Count	12	2	14
about your childs health care?		% within Hispanic or Latino	15.4%	2.3%	8.4%
	Usually	Count	11	10	21
		% within Hispanic or Latino	14.1%	11.4%	12.7%
	Always	Count	50	71	121
		% within Hispanic or Latino	64.1%	80.7%	72.9%
Total		Count	78	88	166
		% within Hispanic or Latino	100.0%	100.0%	100.0%

Table 6. Helpful Staff, White vs. Other

			White Other	vs. Other White, Non- Hispanic	Total
In the last 12 months, how	Never	Count	3	0	3
often were office staff at your childs CRS clinic as		% within White vs. Other	1.4%	.0%	1.0%
helpful as you thought	Sometimes	Count	9	3	12
they should be?		% within White vs. Other	4.1%	4.1%	4.1%
	Usually	Count	30	20	50
		% within White vs. Other	13.5%	27.0%	16.9%
	Always	Count	180	51	231
		% within White vs. Other	81.1%	68.9%	78.0%
Total		Count	222	74	296
		% within White vs. Other	100.0%	100.0%	100.0%

Table 7. Staff Listens, White vs. Other

			White Other	vs. Other White, Non- Hispanic	Total
In the last 12 months, how	Never	Count	4	. 0	4
often did the CRS clinic staff listen carefully to you?		% within White vs. Other	1.8%	.0%	1.4%
Stair listeri carefully to you?	Sometimes	Count	10	10	20
		% within White vs. Other	4.5%	13.5%	6.8%
	Usually	Count	27	15	42
		% within White vs. Other	12.2%	20.3%	14.2%
	Always	Count	181	49	230
		% within White vs. Other	81.5%	66.2%	77.7%
Total		Count	222	74	296
		% within White vs. Other	100.0%	100.0%	100.0%

Table 8. Providers Answer Questions, White vs. Other

			White vs. Other		
			Other	White, Non- Hispanic	Total
In the last 12 months,	Never	Count	2	2	4
how often did you have your questions answered		% within White vs. Other	1.0%	2.7%	1.4%
by your childes CRS	Sometimes	Count	10	4	14
doctors or other health		% within White vs. Other	4.8%	5.4%	5.0%
providers?	Usually	Count	26	13	39
		% within White vs. Other	12.6%	17.6%	13.9%
	Always	Count	169	55	224
		% within White vs. Other	81.6%	74.3%	79.7%
Total		Count	207	74	281
		% within White vs. Other	100.0%	100.0%	100.0%

Table 9. Providers Give Information, White vs. Other

			White		
			Other	White, Non- Hispanic	Total
In the last 12 months,	Never	Count	6	1	7
how often did you get the specific information you		% within White vs. Other	3.0%	1.5%	2.6%
needed from your childs	Sometimes	Count	8	5	13
CRS doctors or other		% within White vs. Other	4.0%	7.4%	4.9%
health providers?	Usually	Count	32	16	48
		% within White vs. Other	16.1%	23.5%	18.0%
	Always	Count	153	46	199
		% within White vs. Other	76.9%	67.6%	74.5%
Total		Count	199	68	267
		% within White vs. Other	100.0%	100.0%	100.0%

Table 10. Providers Offer Choices, White vs. Other

			White		
			Other	White, Non- Hispanic	Total
When decisions were	Never	Count	6	4	10
made in the last 12 months, how often did your		% within White vs. Other	5.1%	7.8%	6.0%
childes CRS doctors or	Sometimes	Count	7	7	14
other health providers offer		% within White vs. Other	6.0%	13.7%	8.3%
you choices about your childs health care?	Usually	Count	16	6	22
childes health care?		% within White vs. Other	13.7%	11.8%	13.1%
	Always	Count	88	34	122
		% within White vs. Other	75.2%	66.7%	72.6%
Total		Count	117	51	168
		% within White vs. Other	100.0%	100.0%	100.0%

Results to Questions Directly Related to Cultural Competency

Table 11. Courteous and Respectful Treatment by Staff vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
In the last 12 months, how	Never	Count	1	1	2
often did office staff at your childs CRS clinic		% within Hispanic or Latino	.9%	.6%	.7%
treat you and your child with courtesy and respect?	Sometimes	Count	9	3	12
with courtesy and respect:		% within Hispanic or Latino	7.7%	1.7%	4.1%
	Usually	Count	16	8	24
		% within Hispanic or Latino	13.7%	4.6%	8.3%
	Always	Count	91	161	252
		% within Hispanic or Latino	77.8%	93.1%	86.9%
Total		Count	117	173	290
		% within Hispanic or Latino	100.0%	100.0%	100.0%

Table 12. Ease of Discussing Questions and Concerns vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
In the last 12 months, how	Never	Count	5	0	5
often did your childos CRS doctors or other health		% within Hispanic or Latino	4.3%	.0%	1.8%
providers make it easy for you to discuss your	Sometimes	Count	9	6	15
questions or concerns?		% within Hispanic or Latino	7.8%	3.7%	5.4%
	Usually	Count	21	14	35
		% within Hispanic or Latino	18.1%	8.7%	12.6%
	Always	Count	81	141	222
		% within Hispanic or Latino	69.8%	87.6%	80.1%
Total		Count	116	161	277
		% within Hispanic or Latino	100.0%	100.0%	100.0%

Table 13. Understanding Providers vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
In the last 12 months, how	Never	Count	3	1	4
often did your childs CRS doctors or other health		% within Hispanic or Latino	2.6%	.6%	1.4%
providers explain things in a way you could understand?	Sometimes	Count	10	5	15
may you oould underecallar.		% within Hispanic or Latino	8.5%	2.9%	5.2%
	Usually	Count	22	11	33
		% within Hispanic or Latino	18.8%	6.4%	11.4%
	Always	Count	82	155	237
		% within Hispanic or Latino	70.1%	90.1%	82.0%
Total		Count	117	172	289
		% within Hispanic or Latino	100.0%	100.0%	100.0%

Table 14. Respectful Treatment by Providers vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
In the last 12 months, how	Never	Count	2	1	3
often did your childos CRS doctors or other health		% within Hispanic or Latino	1.7%	.6%	1.0%
providers show respect for what you had to say?	Sometimes	Count	10	3	13
mat you had to day.		% within Hispanic or Latino	8.5%	1.7%	4.5%
	Usually	Count	21	12	33
		% within Hispanic or Latino	17.9%	6.9%	11.4%
	Always	Count	84	157	241
		% within Hispanic or Latino	71.8%	90.8%	83.1%
Total		Count	117	173	290
		% within Hispanic or Latino	100.0%	100.0%	100.0%

Table 15. Need for Interpreters vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
In the last 12 months, did you	No	Count	116	87	203
need an interpreter to help you speak with your childs CRS		% within Hispanic or Latino	99.1%	50.3%	70.0%
doctors or other health providers?	Yes	Count	1	86	87
providers?		% within Hispanic or Latino	.9%	49.7%	30.0%
Total		Count	117	173	290
		% within Hispanic or Latino	100.0%	100.0%	100.0%

Table 16. Availability of Interpreters vs. Ethnicity

			Is your child of Hispanic or Latino origin or descent?		
			No	Yes	Total
In the last 12 months, when	Sometimes	Count	1	2	3
you needed an interpreter to help you speak with your		% within Hispanic or Latino	100.0%	2.3%	3.4%
childs CRS doctors or other health providers, how	Usually	Count	0	1	1
often did you get one?		% within Hispanic or Latino	.0%	1.2%	1.1%
	Always	Count	0	83	83
		% within Hispanic or Latino	.0%	96.5%	95.4%
Total		Count	1	86	87
		% within Hispanic or Latino	100.0%	100.0%	100.0%

Table 17. Staff respected my family's religious/spiritual beliefs. (Ethnicity)

		Is your child or Latino desc			
			No	Yes	Total
Please rate your agreement	Strongly Disagree	Count	1	6	7
with the following statement: Staff respected		% within Hispanic or Latino	.9%	3.5%	2.4%
my family's religious/spiritual beliefs.	Disagree	Count	1	0	1
religious/spiritual beliefs.		% within Hispanic or Latino	.9%	.0%	.3%
	Neutral	Count	40	47	87
		% within Hispanic or Latino	34.2%	27.2%	30.0%
	Agree	Count	30	86	116
		% within Hispanic or Latino	25.6%	49.7%	40.0%
	Strongly Agree	Count	45	34	79
		% within Hispanic or Latino	38.5%	19.7%	27.2%
Total		Count	117	173	290
		% within Hispanic or Latino	100.0%	100.0%	100.0%

Table 18. Staff were sensitive to my cultural/ethnic background. (Ethnicity)

			Is your child o		
			No	Yes	Total
Please rate your	Strongly Disagree	Count	1	7	8
agreement with the following statement: Staff were sensitive to		% within Hispanic or Latino	.9%	4.0%	2.8%
my cultural/ethnic	Disagree	Count	2	0	2
background.		% within Hispanic or Latino	1.7%	.0%	.7%
	Neutral Agree	Count	37	38	75
		% within Hispanic or Latino	31.6%	22.0%	25.9%
		Count	29	93	122
		% within Hispanic or Latino	24.8%	53.8%	42.1%
	Strongly Agree	Count	48	35	83
		% within Hispanic or Latino	41.0%	20.2%	28.6%
Total		Count	117	173	290
		% within Hispanic or Latino	100.0%	100.0%	100.0%

Table 19. Courteous and Respectful Treatment by Staff, White vs. Other

			White Other	vs. Other White, Non- Hispanic	Total
In the last 12 months,	Never	Count	2	0	2
how often did office staff at your childs CRS clinic		% within White vs. Other	.9%	.0%	.7%
treat you and your child	Sometimes	Count	6	6	12
with courtesy and respect? Usua		% within White vs. Other	2.7%	8.1%	4.1%
	Usually	Count	15	11	26
		% within White vs. Other	6.8%	14.9%	8.8%
	Always	Count	199	57	256
		% within White vs. Other	89.6%	77.0%	86.5%
Total		Count	222	74	296
		% within White vs. Other	100.0%	100.0%	100.0%

Table 20. Ease of Discussing Questions and Concerns, White vs. Other

	White vs. Other				
			Other	White, Non- Hispanic	Total
In the last 12 months, how	Never	Count	3	2	5
often did your childs CRS doctors or other health		% within White vs. Other	1.4%	2.7%	1.8%
providers make it easy for	Sometimes	Count	11	4	15
you to discuss your questions or concerns?		% within White vs. Other	5.3%	5.4%	5.3%
	Usually Always	Count	25	13	38
		% within White vs. Other	12.0%	17.6%	13.4%
		Count	170	55	225
		% within White vs. Other	81.3%	74.3%	79.5%
Total		Count	209	74	283
		% within White vs. Other	100.0%	100.0%	100.0%

Table 21. Understanding Providers, White vs. Other

			White		
			Other	White, Non- Hispanic	Total
In the last 12 months, how	Never	Count	3	1	4
often did your childs CRS doctors or other health		% within White vs. Other	1.4%	1.4%	1.4%
providers explain things in	Sometimes	Count	10	5	15
a way you could understand?		% within White vs. Other	4.5%	6.8%	5.1%
	Usually	Count	23	13	36
		% within White vs. Other	10.5%	17.6%	12.2%
	Always	Count	184	55	239
		% within White vs. Other	83.6%	74.3%	81.3%
Total		Count	220	74	294
		% within White vs. Other	100.0%	100.0%	100.0%

Table 22. Respectful Treatment by Providers, White vs. Other

	White vs. Ot				
			Other	White, Non- Hispanic	Total
In the last 12 months,	Never	Count	2	1	3
how often did your childs CRS doctors or other		% within White vs. Other	.9%	1.4%	1.0%
health providers show	Sometimes	Count	9	4	13
respect for what you had to say?		% within White vs. Other	4.1%	5.4%	4.4%
	Usually	Count	22	14	36
		% within White vs. Other	9.9%	18.9%	12.2%
	Always	Count	189	55	244
		% within White vs. Other	85.1%	74.3%	82.4%
Total		Count	222	74	296
		% within White vs. Other	100.0%	100.0%	100.0%

Table 23. Need for Interpreters, White vs. Other

			White Other	vs. Other White, Non- Hispanic	Total
In the last 12 months, did you No need an interpreter to help you speak with your childs CRS doctors or other health Yes providers?	No	Count	135	74	209
		% within White vs. Other	60.8%	100.0%	70.6%
	Yes	Count	87	0	87
	% within White vs. Other	39.2%	.0%	29.4%	
Total		Count	222	74	296
		% within White vs. Other	100.0%	100.0%	100.0%

Table 24. Availability of Interpreters, White vs. Other

			White vs. Other	
			Other	Total
In the last 12 months, when	Sometimes	Count	3	3
you needed an interpreter to help you speak with your		% within White vs. Other	3.4%	3.4%
childs CRS doctors or other health providers, how often did you get one?	Usually	Count	1	1
		% within White vs. Other	1.1%	1.1%
	Always	Count	83	83
		% within White vs. Other	95.4%	95.4%
Total		Count	87	87
		% within White vs. Other	100.0%	100.0%

Table 25. Staff respected my family's religious/spiritual beliefs. (White vs. Other)

			White	vs. Other	
			Other	White, Non- Hispanic	Total
Please rate your	Strongly Disagree	Count	6	1	7
agreement with the following statement: Staff		% within White vs. Other	2.7%	1.4%	2.4%
respected my family's religious/spiritual beliefs.	Disagree	Count	1	0	1
rengious/spiritual beliefs.		% within White vs. Other	.5%	.0%	.3%
	Neutral Agree	Count	62	28	90
		% within White vs. Other	27.9%	37.8%	30.4%
		Count	99	20	119
		% within White vs. Other	44.6%	27.0%	40.2%
	Strongly Agree	Count	54	25	79
		% within White vs. Other	24.3%	33.8%	26.7%
Total		Count	222	74	296
		% within White vs. Other	100.0%	100.0%	100.0%

Table 26. Staff were sensitive to my cultural/ethnic background. (White vs. Other)

			White		
			Other	White, Non- Hispanic	Total
Please rate your	Strongly Disagree	Count	7	1	8
agreement with the following statement:		% within White vs. Other	3.2%	1.4%	2.7%
Staff were sensitive	Disagree	Count	1	1	2
to my cultural/ethnic		% within White vs. Other	.5%	1.4%	.7%
background.	Neutral	Count	54	23	77
		% within White vs. Other	24.3%	31.1%	26.0%
	Agree	Count	105	21	126
		% within White vs. Other	47.3%	28.4%	42.6%
	Strongly Agree	Count	55	28	83
		% within White vs. Other	24.8%	37.8%	28.0%
Total		Count	222	74	296
		% within White vs. Other	100.0%	100.0%	100.0%